Narratives of parents of children with ADHD:

a sociological analysis.

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Abstract

This thesis examines and explores the issues around ADHD for parents of children with ADHD. Interviews with parents are analysed using qualitative methods, and supported by data from the Norwegian ADHD magazine.

The first section gives a history of the development of ADHD, and an overview of the Norwegian ADHD Association. Next we consider sociological theories of medicalisation, deviance and the sick role; risk and expertise; and feminist work on ADHD. The method used is qualitative, using both semi-structured in-depth interviewing and analysis of the association's magazine, *Stå På!* These data were analysed using narrative and conversational analysis, with sensitivity to discourses. The interviews were with members from one of the Norwegian ADHD Association's local chapters. They were conducted in Norwegian and transcribed in standardised form. The interviews are considered as stories or narratives with meaning-creating and identity shaping power, and both healing and political motivation. Medicalisation is seen to have advantages and disadvantages, setting this work close to Solvang's "ambivalence perspective" (2007) on medicalisation. Surprises and apparent contradictions in the data material were used to alert the researcher to the tensions and paradoxes around ADHD in the Norwegian setting.

The analysis looks in detail at how the interviewees use narratives to make sense of and frame their situation, particularly through the hero/anti-hero trope. We see how ADHD has become part of a story about fate told genetic/familial terms, and how stigma is negotiated by building up a heroic image of both people with ADHD, and the people who fight the system on their behalves to get them the right help. We see how actors both make use of and reject medical authority and labelling.

This research argues against the suspicion that parents (especially mothers) are primarily motivated to seek an ADHD diagnosis for their children for their own benefit. Further, the data suggests that the 'mother-blame' seen in other studies on is confidently rejected by mothers in the Norwegian context, and connects this to the rights ensured by the Norwegian welfare state.

The interviewees interpret controversies around ADHD as reflecting a lack of information, which they are willing to work at helping to overcome. The parents are preoccupied not with the controversies around ADHD or what others make of their situation, but rather with their children's everyday well being, and future opportunities available to them. *Stå På!* magazine provides a stream of information about medications and the latest

medical research, moral support and encouragement, stories and poems the members can relate to and recognise themselves in, and useful practical information about who to contact in the local area.

This research shows how identity work done by parents of children with ADHD occurs in practice, and how they negotiate the stigma attached to actual ADHD behaviour as well as the medicalised stigma of the diagnostic label. Scientific research is used to establish credibility for the diagnosis and legitimate ADHD as a medical diagnosis, but once this is established they shift focus in favour of pedagogical and social practices that are helpful for assisting learning. Medical, psychological and social understandings of ADHD are therefore not seen as mutually exclusive, but rather as interwoven. ADHD as a biological condition, social role and learning disability are adopted as identity for both those diagnosed, and their families. Further to this, they present the genetic and biological facets of ADHD explicitly relevant to the social and pedagogical realm of school.

Mothers are open about their diagnostic status, as a way of showing solidarity with their children. Those who do not share the diagnosis stand by their children in other ways such as portraying their child and themselves as victims of the previous ignorance about ADHD, pointing out how their high energy levels benefit them (if the setting is right), and rhapsodise about their children's loving natures, charm, and focus on their strengths.

Family histories are re-interpreted in the light of new understandings of genetic predispositions. The parents are aware that ADHD is a modern illness, but this is not interpreted as making the diagnosis any less real. The diagnosis is a powerful sense-making device through which parents can interpret their children's everyday challenges, and through which they can request that their children be seen for whom they are. They seek social acceptance for their children, and their demands for assistance are girdered by medical authority.

In trying to do what is best for their child and avoid the stigma attached to ADHD behaviour, the parents end up with a new medicalised stigma that shadows over the whole family, and narrows their room for agency. They hope they can change this through disseminating information and creating understanding.

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Contents

1. Introduction

This work looks at the experience of parents of children with the diagnosis Attention Deficit Hyperactivity (hereafter ADHD). ADHD is an increasingly frequent diagnosis in Norway, among both children and adults. The characteristics it describes are socially and morally problematic, and particularly undesirable in school and other institutional settings: inattention, hyperactivity, and impulsivity. These are problems many people recognise in themselves. Parents are sometimes portrayed as having their child diagnosed to relieve them of taking responsibility for discipline. The pharmaceutical treatments for ADHD have been the focus of controversies in the mass media. How do parents make sense of these controversies?

In our education-oriented society, much work depends on vocational education; education is no longer only seen as a privilege or a right, but as a necessity. Fitting in among peers is a problem for the majority of people diagnosed with ADHD. As school has become increasingly important - due to requirements for certification - the need has been created for more people to fit in and measure-up to institutionalised standards for longer periods of their lives. How do parents of children with ADHD interpret questions about equality, ranking and individual 'special' needs? Formal education is an important setting where we develop our identity, and schools are a central topic when discussing behavioural problems in children in modern cultures. Norwegian students have the right to adapted education as needed, and the system promotes inclusive education for children with disabilities, although the ideal of full integration of people with mental disabilities was hobbled by the dismantling of central institutions. Special schools have made a slight return in Norway: the deaf, for example, want their own schools. Steiner Schools are a free-standing option and offer their own solutions for various needs.

Claims about ADHD are made in a setting where there is no widespread consensus, and a premise for this research is that parents' actions and decisions have to be taken in a context of ambiguity. In this sense this study is of how parents, as claims-makers or agents of medicalisation, respond to and use various definitions of the ADHD.

Medical sociology is sometimes concerned with de-construction of diagnostic categories. That is *not* what this research is primarily about. Rather, it is about how the diagnosis comes to be meaningful and what changes for the parents of children with ADHD after its application. A premise taken is that people do not primarily want to be seen in terms

of their diagnosis. While diagnoses can be useful and often seen to be factual descriptions of physical conditions, they can also be stigmatising.

ADHD's history

In 1975, Conrad (1975) made a critical analysis of the medicalisation of 'hyperkinesis'. Following the trend of formalisation and institutionalisation of controls of childhood (Conrad and Schneider 1992), certain "inappropriate" or difficult to manage child behaviours went from being 'childhood behavioural disorder', to being thought to have an organic root in the form of 'minimal brain damage' or 'minimal brain dysfunction' (both abbreviated to *MBD*) (Conrad 1975), or 'organic driveness' (Burd and Kerbeshian 1988). According to Conrad, MBD researchers operating in the 1950s "*described a disorder with no clear cut history*" (Conrad 1975: 13), but a history of ADHD has been pieced together. This has also resulted in a discussion between neurologists of whether they should give ADHD a new eponym (see Thome and Jacobs 2004; Budrys 2005; Bilgin, Rémi et al. 2008; Budrys 2008). Heinrich Hoffmann's 1845 children's book "Struwwel Peter" is treated as evidence that ADHD existed then, as now (the ADHD Association even sells it). It has been asserted that:

> *Hoffmann… did not consider this behaviour as a disorder in itself, although he had noted all the details which today would lead to a clear diagnosis. …"Struwwelpeter" can be considered the first description of ADHD symptoms by a psychiatrist and, thus represents an important document of medical history*. (Thome and Jacobs 2004: 305-6)

Since Hoffmann was a psychiatrist, it is easier to accept this conclusion than with parallel literary portrayals of children behaving badly from the same pedagogical tradition, for instance Hilaire Belloc's 1907 "Cautionary Tales".

Concerning the history of the scientific development of the diagnosis, an important milestone came in 1902 when The Lancet published 'Some abnormal psychical conditions in children' which described children with "*an abnormal defect of moral control*", not seeming to be related to improper nurturance (GF Still, 1902, in Iversen 2006: 50). Then in the 1930s through neurological research on shell-shocked war veterans, which in turn led to a diagnosis given to brain-injured children, 'Strauss's syndrome' was defined (Malacrida 2003). Around the same time, amphetamines were tested on children and found to subdue and focus them (Conrad and Schneider 1992). In 1946, 'behavioural problems in children' was described as treatable by amphetamine, along with 38 other clinical uses (Iversen 2006: 29).

Malacrida characterises the discovery of amphetamine treatment for ADHD as a 'serendipitous' result of medicalised normalisation process, as opposed to "*the search for a treatment.*" (Malacrida 2003: 20). By contrast, Conrad and Schneider (1992) focus on formal

and informal controls for badness by the relevant interest groups. Further, Conrad (2006, 1975) argues that the diagnosis was only created after the discovery of the treatment, questioning the motives of pharmaceutical corporations.

The Norwegian ADHD Association

The Norwegian ADHD Association, *ADHD-Norge*, used to be called the MBD (Minimal Brain Disorder) Association. Its name was changed in 2001 to reflect shifts in scientific knowledge. The Association represents people diagnosed with ADHD; Attention Deficit Disorder without hyperactivity (ADD); and Hyperkinetic Disorder. For the purposes of this research, all these subcategories are referred to under the umbrella term, ADHD.

The Association is described on their website as both a support group and a political interest group that aims to assist its members by providing information about what assistance is available from the public system, and furthering understanding of ADHD among the general public. Membership costs 350 kroner per annum with rebates for members from the same household, and includes *STÅ PÅ!* (‘*Hang in there!*’, hereafter written as Stå På) magazine four times a year with the latest medical and educational research updates, invitations to conferences, articles by readers, book reviews, and contact details of the Association’s local chapters and telephone numbers of members who have volunteered to be available to talk to or seek advice from.

The Association organises meetings where people can gather and discuss ADHD issues; they also organise summer camps for kids. *ADHD-Norge* is a not-for-profit organisation funded through membership, raffles, and contributions from the national lottery. It is connected to the *National Competence Centre for AD/HD, Tourette’s syndrome and Narcolepsy* at Oslo University Hospital.

2. Theory and literature review

This chapter examines sociologically relevant work on ADHD, including theories of medicalisation and stigma, risk and intervention, and the concepts of 'the Ritalin track', 'mother-blame', and ideal typical welfare states.

Medicalisation

Medicalisation is the process whereby states of being and of the body are defined in medical terms. It is an individualistic, reductionist perspective on a range of states of being and personal experience, that individualises social problems (Lian 2006). One such problem, is deviant behaviour. Deviance is a relational concept, existing only under certain social conditions and in comparison to normality. As such, deviance is an attributed characteristic or conferred status, imputed onto 'the deviant' by the people around them. "*The medicalisation of deviant behaviour*" refers to defining a collection of personal traits or behaviour that transgress social boundaries as illness, and labelling the individual as a sick deviant rather than a bad deviant (Conrad and Schneider 1992).

Because of the medical establishment's expert status, we grant it authority over our state of being, and the power to define us as healthy or ill, normal or deviant (Lian 2006). Medical authorities intervene beyond what medicine is able to cure, and its area of responsibility has reached a point where anything involving the body or emotions can become a problem for the medical service (Illich 1975). This is the pre-condition for the "*wholesale therapeutisation of everyday life*" (Melucci 1996) and medicalised personal identity. Medicine neither answers moral questions, nor illuminates social issues, yet it has authority and is difficult to question. Medical authority and the knowledge "communication gap" (Parsons 1979 (1951): 441) it symbolises between expert/layman and doctor/patient is part of the 'expropriation of health' (Illich 1975) that renders us reliant on administered medical therapies rather than empowered, autonomous self-healers (Illich 1975; Melucci 1996; Lupton 2003).

While disease concerns the condition a person suffers from, sickness is a social role. Parsons explains how the sick role grants two exemptions and imposes two responsibilities: exemption from responsibilities, and not being expected to recover by an act of will; but the sick person must want to get well as quickly as possible, and seek and cooperate with technically competent help (Parsons 1979 (1951): 436-437). The sick role should properly relieve one of certain responsibilities, but avoidance of duties is widely considered immoral;

so sickness is seen as having 'secondary benefits' which can be unconscious motivators for seeking the sick role (ibid).

The conflict perspective sees the medicalisation of deviance in terms of competing interest groups trying to further their interests. Conrad and Schneider write: "*Sinful and criminal deviants are responsible for their behaviour; sick deviants are not*" (1992: 27). This absolving, liberating aspect of sickness attached to deviance gives parents an interest in seeking a sick role (or a modified version of it) for their children's sakes and for their own sakes: that their children are absolved of some responsibility; and that their parenting is not directly blamed for their children's bad behaviour. Further, the paradigm through which the deviance labelling takes place means a particular authority will be appropriate for governing the deviance (ibid.), so having a diagnosis from a doctor can be used to disempower or question educator's authority.

The definition of norms and deviance, and application of social controls, is political. The dominant definition of problematic behaviour in children is the result of claims made by interested parties. Their claim covers both a set of internalised social facts about a phenomenon and their morality. Conrad and Schneider's view of deviance as an outcome of the moral parameters set by those who have the power to define normality points out that it is weaker groups who will be defined as deviant. Medical treatments then become a valid source of social control, which Parsons has defined as, "*the control of promotion of conformity*" (Conrad and Schneider 1992: 7). Normality is maintained by both informal social controls, which are self-controls and relational controls; and formal social controls, which are institutional (Conrad and Schneider 1992: 8).

Conflict perspectives on medicalisation have pointed out that pharmaceutical companies that fund research into the disease and its treatments have a conflict of interest (Conrad and Schneider 1992). The pharmaceutical industry is a result of and benefits from medicalisation. It also has a role in selling us back our peace of mind, which has been compromised by risk information (Melucci 1996), but research into the link between ADHD and risk of criminality rely on retrospective diagnoses of prison populations, blurring causality with correlation. Also, ADHD was initially constructed as a childhood developmental condition; but the diagnostic frame has been expanded to include adults who seek out the diagnosis to explain failures (Conrad and Potter 2000), including "self-medication" with illegal drugs. This has further broadened the market. In Norway in 2008, Ritalin was sold for 125.6 million kroner, and methyphenidate sold as Ritalin and Concerta was the 25th most sold pharmaceutical in Norway in the first half of 2007 (Apotekforeningen

2007: 50). Moral concern about drug therapies for ADHD has been topical in Norway. The theme taken up in Sivertsen and Tranøy's (2007) "*ADHD: pills going astray*" recurs in news reports (see App.6); and conflicts of interest between pharmaceutical companies, doctors, and Norway's *National Competence Centre for ADHD, Tourette's and Narcolepsy* have been brought up for discussion in parliament (Stortinget 2006).

Promotion of conformity and social control through medicalisation has also been critiqued by the 'anti-psychiatry movement', fuelled by a combination of a strong desire for freedom from oppression, and moral outrage about harmful drugs. The diagnostic criteria provided by the DSMs has been criticised for consisting only of an openly-worded checklist of ordinary but undesirable behaviour, prefixed with "often" (see appendix 5). This criticism is typical of a broader critique of the role of psychiatry in redefining problems, and bringing people involuntarily under disciplining conditions (Rose 1999). Criticisms are also directed at the allopathic diagnosis (that is, by trying a treatment and seeing if it works). However, the pharmaceuticals that are used to treat ADHD also have a "behaviour enhancing" effect on children *without* ADHD. This leads critics to assert there is no "paradoxical effect" of amphetamines, and the diagnosis is interpreted as an artefact of its treatment (Conrad 2006; Timimi 2005). Further, there are some questions remaining regarding side effects (CMPH 2009; Legemiddelverket 2009).

It has been argued that there is no organic evidence for ADHD: although theorised to have its root in brain functioning and genes, no differences have been found with other brains of the same age, and no gene has been mapped (Timimi 2005). There is a contradiction inherent in the idea that, one on hand, ADHD is a physiological developmental psychiatric condition; but on the other hand at some point children must learn to "behave" and "control themselves". That ADHD treatment usually involves amphetamines (in addition to psycho-social therapies), adds unease to a diagnosis already viewed for some as an instance of undignified classification, labelling, and rejection of difference. ADHD's amphetamine treatment is easily portrayed as an irresponsible choice with harmful implications.

The foundation of medicalisation as a critical concept is that it smoothes over and covers up problems; and in doing so, can create others, to the point of disabling us (Illich 1975). We have already discussed how disease is biological and sickness is social. So too, a distinction needs to be made between impairment and disability. While impairments are physical, disabilities are what these impairments are taken to mean in social practice. According to the social or relational model of disability, "*people with impairment are disabled by society, not by their impairments*" (Thomas 2004: 573). For schools this would

mean that learning difficulties occur in and because of the school setting. Thus learning difficulties would not be reduced to individual problems, and the individual should not be labelled; because, in fairness, the parameters of education have to be broad enough to include everyone (Nes 2000). Dominant professional experts and medical culture have often been seen within the critical-dialectical disability studies field as limiting the agency of the individual and playing an influential part in making impairments into disablements. Because of this,

> there is a strong belief… within the disability movement, that the concept of empowerment should challenge the power of professionals (Christensen 2010: 248).

Therapies, in turn, should be judged by whether they encourage independence (autonomy) or create dependence (Melucci 1996: 86). The social model of disability, which is promoted by disability advocates as enabling inclusion, requires that people not be made disabled by impairments, and not be made deviant by normalising processes that categorise 'normal' under increasingly narrow terms. Emancipation and independence are basic norms behind the social model of disability.

Conrad and Schneider (1992) do point toward the empowering possibilities of aligning with the diagnostic paradigm, but the context Conrad and Schneider list their 'bright side' in is such that the empowering aspects of medicalisation can easily be misread as sly or somewhat distasteful, and work following this theoretical thread also illuminates the moral gains involved in getting a diagnosis. Medicalisation as a concept has led to important critical understanding of the pharmaceutical industry, but perhaps because the vocabulary is so radical it becomes difficult to nuance. We now turn to consider the bright side of medicalisation.

Bright side

Are there good reasons for parents to seek a diagnosis for their child? Generally, children are sent to school for socialisation and education to equip them for adult life. When a child is so unruly that nobody can handle them, or so vague and unconnected with their surroundings, and this is to the degree that they can spend years in school without being socialised and without learning anything except that they are bad students and unpopular with others, many would argue that it would be wrong to deny them a drug that will ameliorate that. In this way, *medical diagnoses can be seen as playing a humane role*.

ADHD was only defined in modern times under particular cultural conditions; but this is *not* to say that it has no biological underpinning, or that there is no difference between people's brains, rather *it is the cultural context that determines what meaning or importance*

our biology is given. Our biological premises and the meaning attributed to them can be usefully understood as what Beauvoir called a 'situation' (Moi 1999). Just as the distinction between sex and gender can overshadow the lived experience of a body and the process of becoming, so too can an overemphasis on social aspects of ability dim our sensitivity to the contingencies of what we experience; parallel to Beauvoir's, "*one is not born a woman*" (Moi 1999), ADHD as a status also consists of contingent experiences. The concept of negotiation sensitises us to how interpretations vary as social orders are used, alluded to, and rejected. These negotiations are contingent on, most importantly, the options available to work with (Strauss 1978). All people are in a situation where there is feedback between their individual psychology, physiology, and environment. Moi (1999) and Mead (1964) share, in a way, views of human nature and the body, where it is a background, or a social vehicle with the ability to express impulses, interact socially and communicate. These approaches are sensitive to understanding the interaction between physiological body, identity, and social processes that work on people.

Strydom recommends constructivism be used in a way that acknowledges the objectivity of reality; this call is echoed by Turner's idea of illness and vulnerability as a quiddity, and Illich's acknowledgement of our fragility (Illich 1975; Strydom 2002; Turner 2004). We can consider for example the case of autism, a condition that was previously attributed to mothering practices, for which it is now accepted there is an organic basis. Scientists think that people at the ADHD end of the behavioural spectrum have certain brain characteristic to a larger or lesser extent than people who would not be given the diagnosis after proper assessment, and for social scientists, these scientific biological facts are a "black box" (something we take as an unknown). What sociology has as its area regarding such biological black boxes is in the analysis of what the diagnosis means in social practice. The diagnosis ADHD is 'plastic', as are all medical diagnoses (Atle Møen, 2009, pers.comms.). In part, a diagnosis has definite biological aspects, but what these are taken to mean in social practice are culturally determined 'grey-areas'. That is, what a diagnosis means can be formed and changed (Conrad and Schneider, 1992).

Stigma and ambivalence

In a discussion of dyslexia, Solvang illustrates the liberating aspect of diagnosis with a quote from a relieved recipient, "*It was good to find out what it was, and that it wasn't me*" (Solvang 1999, my translation). This relief of the person cited is indicative of the moral

absolution associated with the sick role. In a study of special education experiences in Sweden it was concluded that:

> The positive aspects of a medical label were related to a perception that a diagnosis could get them extra resources for special support in school, but it did not always have the de-stigmatising effect one would expect in terms of leading to enhanced self-esteem and the removal of blame from the pupil and the parents. Sometimes it caused stigma, or at least ambivalence. (Isaksson, Lindqvist et al. In press: 17)

The labelling that occurs through diagnosis creates expectations that strengthen the sickness and the imputed deviance (Conrad and Schneider 1992). The diagnostic criteria describe behaviours that is recognisable in most people, so that the diagnosis is seen as putting a label on what is "normal" behaviour (Breggin 2001; Conrad 2006).

Goffman has written that stigmatising illness can be

> the 'hook' on which the patient has hung all inadequacies… and he has come to depend on it not only as a reasonable escape from competition but as a protection from social responsibility (1963: 21)

Can someone with a stigmatised condition manage to pass as normal? Or, should that person come forward and become visible as different for the relief it might afford? The price of this could be various forms of discrimination, and the risk of a 'spoilt' identity (Goffman 1963). This is the dilemma to be negotiated by people with a stigma. Whether they choose to be open or to cover it up, will have an impact on whether they are accepted or rejected.

Risk

Just as deviance is a relational concept, so too can 'risk factors' be determined by assessment of patients against a normal population. Risks create a pretext for "potentially infinite" (Castel in Lupton 1999) expert intervention for management and control from health and social workers. Beck theorised that disintegration of the traditional society that deferred to religion, makes contemporary risk societies more accepting of the convincing power and authority of the paradigm of expert knowledge (Beck 1992). Thus, authority for what is really the true self is no longer primarily framed in spiritual terms. Rather, The Self is an individual project, and a medical one, framed in risk terms (Melucci 1996; Møen 2002; Turner 2004). When in doubt people want to seek experts, and when in a dilemma between different expert knowledges, they most often defer to whoever is the better expert (Giddens 1990; Kerr and Cunningham-Burley 2007). The more doubt arises, the more they require expert guidance. This reliance is fear-driven and becomes increasingly relevant as people hear about potential threats of which they are largely ignorant, but feel they cannot afford to ignore (Beck 1992; Beck 2000; Giddens 1990); this in turn results in an ambivalent and sceptical "questioning

public" because the experts are seen to disagree on important matters (Giddens 1990; Lupton 1999; Lash 2000).

Expertise has been characterised by Rose as a problem throughout 19th and 20th century in the way it imposes moralising representations of values (Rose 1999). Mothers in particular were identified as needing expert help; such that families could not feel self-assured of their capability to raise a child decently without drawing on expert information. Being moral necessarily involves subjectification and techniques of the self to transform and liberate the individual (Foucault, in Rose 1999) to become their 'true self', "*through the passage of the therapeutic*" (Rose 1999:243).

Risky life-course

"Well-being for children cannot be limited to their condition in the present. The present in which they live influences their development in the future… The understanding and conceptualization of children's quality of life has to encompass the quality here and now and the dimensions of socialization and development. Being influences becoming; becoming influences the understanding of being." (Frønes 2008: 9)

ADHD is seen as a risky start to the successful, happy life that one must take the responsibility of having (Beck-Gernsheim 2000), and is portrayed as being at the root of deviant careers. Children with ADHD are not always portrayed as deviant in the literature about them, but rather as being at risk of *becoming* criminally deviant in future. Inappropriate classroom behaviour and other ADHD symptoms are seen as risk-indicators, or harbingers, of potential disaster. If parents do not comply with the therapeutic options on offer, they may get the impression their children risk drug addiction, social isolation, committing rape, general criminality, mental illness and unemployability[1] (Malacrida 2002). The therapeutic option of Ritalin de-animates these risks. Singh has looked at the dilemmas parents face, and called the image that accompanies medical therapy, "*the Ritalin track*" (Singh 2005). A troubled child who receives no expert intervention for their problems has a risky future, compared to a child whose problems are defined as illness, who gets expert support and medical treatment, and thereby avoids danger. So, the therapeutic option is seen as a safe way to happiness, as opposed to the dangers and parental culpabilities of the other, riskier path (Singh 2005).

[1] ADHD is 'guilty by association' of these things as the retrospective diagnoses given to prison inmates link criminality with ADHD. Malacrida, C. (2002). "Alternative therapies and Attention Deficit Disorder: Discourses of maternal responsibility and risk." Gender and society **16**(3): 366-385.
, Timimi, S. (2005). Naughty boys: anti-social behavior, ADHD, and the role of culture. New York, Palgrave Macmillan.

Singh (2005) suggests that context-specific use of ADHD medicines illustrates the great extent to which we form ideas about our 'authentic' self at school: for instance, that the authentic "I" should be competent and well-behaved. The people in her study saw themselves as needing treatment for their behavioural disturbance in the same way "diabetics need insulin" or others "need glasses". One puts on glasses as necessary: so too, students take Ritalin for mathematics classes, but do not take it on the weekends (ibid). Authenticity has been an important notion in how we think about children. It is associated with Romantic Developmentalism and the Enlightenment period from where influential ideas about children as innocents with the right to adult protection come (Johansen 2009). Interpretations of authenticity, or who people think they 'really are', are changed with time and culture.

Authenticity is sometimes seen as corroded by excessive self-regulating techniques. 'Edgework' is the term used (Lyng 1990 from Hunter S. Thompson, in Lupton 1999) to describe pushing the boundaries from the safe and known, into risks. Edgework denotes deliberate risk taking, only undertaken by people with an innate mental toughness. Similar 'transcendental behaviour' was encouraged by the Romantics (Lupton 1999). So here we see there is an interesting tension between 'achieving' the authentic self through transformative therapeutic passages, or seeing the authentic self Romantically as unconstrained from self-regulation.

Genetic fate: the dark-side of medicalisation

Increased knowledge about the human genome has led to an emphasis in technical literature on the genetic component of behavioural problems. Genes contributing to an 'ADHD brain' can be inherited as other physiological characteristics can. This has enabled parents, or forced them, to think of their child's difficulties as genetic in origin; as not only biological, but running in the family. The 'traditional' challenges associated with raising a successful child have become modern risks associated with biological fate (Rose 2000).

For the fathers of children with ADHD interviewed by Singh (2003; 2005), their genes were not morally neutral. Fathers tend to see ADHD as a reflection of who they were when they were young, not as a disease; instead explaining hyperactive 'bad behaviour' with truisms like "boys will be boys". They felt that if their boys were poor at sports it reflected badly on them personally. This is seen as an example of how understandings of our genetic makeup are subjective, and given meaning through culture; genetic conditions are more permanent, unavoidable, and "staining" than other transient forms of disease. As Lian puts it, "*the risk of illness is no longer merely a risk, it has become an illness itself*" (Lian 2006: 83,

my translation). Seen in this way, bio-genetic understandings of ADHD position it not only as a risk or fate, but are stigmatising in addition.

Mother-blame

Medicalisation changes who or what is blamed for children's bad behaviour, and gender is identified as a pivotal issue in several items of literature (see for example Rafalovich 2001; Malacrida 2003; Singh 2003; Malacrida 2004; Singh 2004; Singh 2005; Timimi 2005; Singh 2006; Blum 2007; Carpenter and Austin 2007). Feminist studies of the experience of mothering children with ADHD or 'invisible disabilities' has been concerned with the interaction between women and professionals, and women's experience of being blamed for their children's perceived shortcomings is central. Feminist literature on mothering ADHD children argues that when children are seen as deviant, mothers are blamed as incompetent or pathological; and the subjective experience of mothering a child with behavioural problems is burdened with stigma and feelings of culpability.

Without medicalisation, blame rests with the individual and their family and it has been argued, particularly the mother. According to Claudia Malacrida,

> For the vast majority of ADHD sceptics… the causal equation between bad parent (mother) and troubled child is seen as a direct one (2003: 103-104).

Malacrida clearly conceptualises 'mother-blame' as a dominant cultural phenomenon. Comparing experiences of mothers of children with ADHD in England and Canada, she details the appalling extent to which the mothers in her study were assumed to be the cause of their children's problems. It was typical that before, during and after their child's assessment for ADHD, the tyrannical gaze of the 'helping professionals' was directed at them. They were seen as bad mothers both in specific circumstances relating to their own child, and also got to hear through media portrayals of ADHD and careless comments that mothers of children with ADHD were at fault for their child's problems: by failing to provide care or moral guidance at home; by being assumed to have drunk during pregnancy; by being pushy, wanting too much and not accepting their child as they were. Further, the burden of disciplining and being responsible for their child's behaviour was often born alone, even when there were other adults present. Malacrida shows how an individual's feelings of self-doubt, guilt, shame, and unworthiness (as felt by the mothers in her study) were symptomatic of cultural conditions (Malacrida 2003).

In studies of mothering children with ADHD carried out by Malacrida (2003), Blum (2007), and Carpenter and Austin (2007), we see evidence presented of what Blum calls "relentless care". Blum argues that in order to be seen as living up to the demands of myths

about mothering, mothers of children with 'invisible disabilities' become 'vigilantes' working to secure services for their children and to defend their mothering capabilities (Blum 2007). This involves cooperation with professional experts. In my reading, the mothers go into what Parsons called the 'complementary role' played by patients in the doctor-patient relationship, on behalf of their children. As mentioned previously, the fourth element of the sick role is the obligation to cooperate with those who are technically competent to help (1979 (1951): 437).

Agreeing with people in authority, despite misgivings, is an important part of being seen to be cooperative. While laymen in general can be seen to act in accord with, counter to, and despite expert knowledge (Wynne 1996), mothers engaging with professionals may be subject to additional constraints: non-cooperation with professionals can jeopardise their children's chances of getting adequate assistance (Malacrida 2003). Malacrida sympathetically portrays mothers as accepting blame for their children's problems on themselves, for their children's sakes. Medicalisation appeared to *partly* take blame away from mothers, but this did not mean when a problem remained that anybody necessarily listened to them. Malacrida found that

> professionals believe that professional knowledge about what normal and abnormal childhood looks like is taken as superior to what a mother's knowledge about her own child might be (ibid.: 136).

Experts can be unsatisfactorily fallible, giving vague diagnoses that left mothers to deal with contradictions and ambiguities; but in the final analysis, the mothers are left with their actions constrained by the belief that they need to "*keep professionals on-side*" (ibid.: 241), and 'play ball' with the expert team. That is, expert knowledge was superior because of the power behind it, not because it was necessarily considered closer to the 'Truth'. As laymen, mothers risked becoming the subject of inquiry themselves when they presented their children as having problems (Malacrida 2003).

Singh (2004) takes a slightly different focus on mothers' silences and acceptance of blame. She interprets it as an act of self-preservation, but one which furthers the "motherhood myth" that attributed blame to them in the first place. Interesting silences are also revealed in Singh's work on fathers' perspectives of their ADHD children. Singh points to reasons for fathers, sceptical as they may be, to hold their tongues about the ADHD diagnosis: marital harmony is protected by the benefit their wives receive from the child's diagnosis, and their relationship with their sons is possibly also stake (Singh 2003). Fathers appear reluctant to interfere (Singh 2004). Thus mothering appears clearly in the literature as a fraught social role, laden with motherhood myths which hold that child-raising should be a mother's natural

ability; and expert knowledge about 'behavioural problems' and 'learning difficulties' overlaps with the motherhood territory.

This research falls into a category where parents become research objects because of their children. For ethical and possibly psychological reasons concerning the researcher's discomfort, research tends to be on the children's parents, rather than on the children themselves (Lundeby 2009). Singh repeatedly mentions the absence of the consideration of children's perspectives on their illness, label and medicating as an ethical problem (Singh 2003; 2004; 2005; 2006), and points out the absurdity that it is ethically problematic to interview children, but they can be taken for psychiatric evaluation and have drugs administered without their consent. Despite this it remains worthwhile to research parents. As Lundeby (2009) points out, mothers in particular often act as mediators and interpreters on their children's behalves, and are good sources of information. Parents have a different perspective on their children's needs than the children themselves, but it is not necessary to see them as in conflict with their children (Lundeby 2009). This is consistent with the approach taken by Malacrida (2003) and Isaksson et alia (In press), who interpret mothers as having a type of expertise, based on their intimate knowledge of their children's condition.

The Welfare state and women

We now turn to consider some cultural differences in the situation of the Norwegians interviewed for this research project, compared to those in Malacrida or Singh's aforementioned works. In doing so, we will contrast the basic features of the liberal welfare states where Malacrida and Singh carried out their research on mother-blame and guilt feelings – Canada and England - with the Nordic model. 'Liberal' refers to those welfare states where welfare arrangements are closer to 'poor relief', and are characterised by means-testing and modest welfare payments. The "liberal welfare state", as a theoretical concept, stands in contrast to the other two ideal forms, of "social democratic welfare state" and "conservative welfare state" (Esping-Andersen 1990).

Liberal policy tends to encourage funding of research into family breakdown and bad parenting instead of taking directions that assist working families with children. It is acceptable and desirable to governments in the English-speaking liberal welfare states to map out social disintegration (Brannen 1999). This official line is reflected in dismay about poor parenting. ADHD has become synonymous in mass media reportage with bad behaviour; the "illness" is suspiciously like an expedient solution and explanation to problems probably avoidable with the right combination of attachment parenting (especially from mothers) and

discipline (especially from fathers). Liberal public policies emphasise personal responsibility, including provision of care for family by the women in that family, not by collective arrangements (Turner 2004). In short, changes in family patterns are seen from the liberal perspective as inherently problematic. Conservative approaches seek to protect the child's best interests by retaining mothers as having the main responsibility for children's welfare; this at the cost of recognising households' economic imperatives and in turn providing families with conditions that enable mothers to participate in paid work without concerns for their children (knowing their children are being adequately cared for without them) (Brannen 1999; Smart 1999).

By contrast, women's liberation has been relatively successful in Norway, with public policies aimed at maintaining mothers' connection to the paid workforce. Important examples of such policies are: guaranteed access to day-care for small children; and 12 month's paid maternity leave from work. Norway has the world's highest proportion of women in paid work, and women are sometimes seen as being those who stand to benefit most from the welfare state (Fraser 1989; Nagel 1998). In the Nordic "social democratic welfare states", collective means are proactively distributed to increase social equality. This was made possible by the cultural shift that occurred in Scandinavia following WWII, from seeing welfare payments as alms, to seeing them as entitlements earned through citizenship. The coinciding of, on one hand, the aims of the 1970's women's liberation movement with, on the other, the "workfare" system's desire for maximum workforce participation, has resulted in an emphasis on economic equality and promoted wage compression. This has been called "state feminism" (Hernes 1987).

While the 'friendly to women' (Leira 1998: 187) aspect of the Nordic model welfare state is an important feature, it also must not be exaggerated. Esping-Andersen (1990) has been criticised for overlooking the strongly gendered aspects of care as an institution, and the large role played by the family in the production of welfare (Leira 1998; Nagel 1998). Motherhood is also myth-laden in Norway. Ellingsæter argues for example how the test of real motherhood is seen to be how women respond to their newborns, and further how well women live up to the ideal. Mothering instinct can be seen as natural to all women, or a talent; so those who do not display it are accordingly considered either unnatural or untalented (Ellingsæter 2004). However, while the sexual division of labour persists both in paid and unpaid care provision in Norway, Norwegian social policies reflect that women do not have to bear responsibility for child-raising and child-care alone. Family and kinship still play a role, but Norwegians have the right not to depend on them. As members of a 'socialist democratic

welfare state', they are entitled to a wider array of rights as citizens – not only in their role as mothers, but also concerning their education, health, retirement, and employment security.

It is debateable to what extent it is fair to characterise the Anglophone countries as sharing a culture or political inclinations (Esping-Andersen 1999); but the English-speaking countries do, broadly speaking, share neo-conservative views of the individual and their responsibilities, particularly in the private domain, that is questioned in Scandinavian countries. Certainly, it can make sense to make use of this generalisation from the Norwegian standpoint, even if it may seem far too general when considered within the Anglophone constellation it concerns. Thus, two tendencies to cultural difference between Norway and the liberal welfare states have been pointed out: the differently-gendered aspects of the institution of Care; and welfare as a right and an earned entitlement. Taken together, these suggest the culturally bound nature of motherhood: that is, the category 'mother' cannot be assumed to be the same across all cultures.

Access to adapted education

In many countries, a legal distinction is made between a diagnosed Learning Disability and difficulties learning. Conrad and Schneider (1992) have duly pointed out that it is not until children's conduct is successfully defined in biological terms and the authority for ADHD transferred to the medical establishment, the "mode of intervention" of increased educational services becomes justified. However, in Norway a distinction between learning disabilities and difficulties is not always made, because all students are entitled to have their education adapted to their learning needs by law. [2] The Norwegian 'unitary' school system is organised with equality as a central ideal, and disability does not have to be present in order to entitle students to special education measures. Keywords in the Norwegian context are *tilrettelegging* and *tilpasset opplæring*, meaning facilitation and adapted education

2 The law on discrimination and access or Lov om forbud mot diskriminering på grunn av nedsatt funksjonsevne (diskriminerings- og tilgjengelighetsloven), Section 12 states, *"Skole- og utdanningsinstitusjon skal foreta rimelig individuell tilrettelegging av lærested og undervisning for å sikre at elever og studenter med nedsatt funksjonsevne får likeverdige opplærings- og utdanningsmuligheter*" and *"Brudd på plikten til individuell tilrettelegging etter første til femte ledd regnes som diskriminering*", in paragraphs 2 and 6 respectively. Secondly, the law on teaching, Opplæringsloven, states in section 5, paragraph 1: "*Elever som ikke har eller kan få et tilfredsstillende utbytte av det ordinære opplæringstilbudet, har krav på spesialundervisning*". Thirdly, Lov om grunnskolen, paragraph 1-3 states: *"Opplæringa skal tilpassast evnene og føresetnadene hjå den enkelte eleven, lærlingen og lærekandidaten*". Finally, "*det [er] et offentlig ansvar å legge til rette for at alle ut fra sine forutsetninger får lik mulighet til å skaffe seg gode levekår og til å ivareta sine rettigheter og plikter som samfunnsborgere. Samfunnsskapte hindringer er ifølge innstillingen årsaken til at mange funksjonshemmede ikke har mulighet til deltakelse og likestilling."*
Barne-og likestillingsdept. (2008-2009). "Riksrevisjonens undersøkelse av adgang til samfunnslivet for personer med funksjonsnedsettelse. [Office of the auditor general in Norway's investigation of access to social life for people with disabilities]" Dokument nr. 3:10 (2008/2009) Oslo, Riksrevisjonen.

respectively. What actual measures should be taken to suit education to students' needs is decided through assessments by pedagogical experts from the Practical Education Service (*praktisk-pedagogisk tjeneste*, PPT), resulting in Individual Learning/Education Plans (ILPs or IEPs). Despite this, there seem to be discrepancies between legal entitlements and actual provision. It seems that in practice, a diagnosis is legally clearer and has more clout than a 'difficulty' – even in Norway. Further, it has been argued that IEPs identify the individual as having the problem, not the school (Isaksson, Lindqvist et al. 2007).

Possibilities are a driving force behind medicalisation (Lian 2006). Dyslexics who have gone to court regarding 'lost possibilities' have won damages in about one-third of cases: the legal argument is that in failing to acknowledge or give the diagnosis of dyslexia, the schools failed to employ the diagnosis's perceived de-stigmatising power. The schools did not fail them in the sense of their literacy level; nor had they failed them in any "curative" sense, since it is understood that dyslexia is not a "treatable" condition. Had they done acknowledged the dyslexia, it would have changed the students' self-perception, and they would have been more self-confident and had greater possibilities in education and work. The dyslexics who go to court are concerned about their prescribed social role, not their literacy per se. But the rationale that a diagnosis is de-stigmatising is disputable (Kolbjørnsen 2003; Solvang 2007; Isaksson, Lindqvist et al. In press).

To summarise, this chapter has shown how medicalisation, therapeutisation, the sick role and secondary benefits and stigma/fate connected to it, genes, authenticity, risk, and mother-blame are key issues for understanding the experience of parents of children with ADHD diagnoses sociologically. They are interconnected cultural aspects that shape illness experiences and sickness motivation.

3. Methods

This chapter gives an overview of how informants were located; qualitative methodology and research techniques; and the hermeneutic approach. We then turn to consider concrete factors that influenced how the research evolved, and consider the ethical status of this research.

Data from interviews and Stå På

After receiving ethics approval from *Norsk Samfunnsvitenskapelig Datatjeneste* (NSD), I contacted a representative of the Norwegian ADHD Association and asked whether they thought any members would be interested in being interviewed. A committee member invited me to attend an ADHD meeting so that I could introduce myself and what my objectives (appendix 1). The atmosphere at the meeting was warm and intimate, being as it was in a small room with fifteen people. At the end of my presentation I asked if any parents in the group would be willing to talk to me about their experiences, and passed around a sheet of paper and a pen for their telephone numbers and email addresses. I got eleven names. I had mixed success in following-up the contacts I got that night: in the end, seven agreed to be interviewed. The other four declined by not returning my messages or emails, which was respected. The seven interviewees are:

- Anne -mother of two with ADHD diagnoses; has ADHD herself
- Monica -mother of two, one with an ADD diagnosis; has ADD herself
- Hege -mother of two with ADHD diagnoses
- Nina -mother of one with Hyperkinetic disorder
- Hilde -mother of one with ADHD; and has ADHD herself
- Jan -father of one adult with ADHD
- Anita -mother of one adult with ADHD; has other children without diagnoses.

To arrange the interviews I emailed to ask if and when people were available, and explained my constraints, in particular my reliance on my husband being home from work to baby-sit. To my delight, I got a few responses encouraging me to bring the baby along to the interview! It was agreed it was probably easier to have a baby around than children or teenagers who are freshly home from school and waiting for dinner, and so on. In the end, four interviews were carried out with a baby present, either on my lap or crawling around; three of these at their homes, one at a work-place lunchroom. The last three interviews were baby-free and conducted at FFO, *Funksjonshemmedes felles organisasjon* (a disability advocacy organisation).

The interviews were recorded on an MP3 player; a technical problem resulted in failure of the player to save the recorded file. Detailed notes from this interview were used to reconstruct the interviewee's most memorable views. I email my field notes to the interviewee, and she agreed I had not misrepresented her.

The ADHD Association newsletter, Stå På ('*Hang in there*'), has been used as documentary material. Stå På is a document posted out to all interviewees, as this is included in membership of the association. While over ten hours of recorded interview material (almost 12 hours including the lost recording) constitutes solid data material, the members' magazine, Stå På, adds substance and is interesting material because it is a shared source of information among the members of *ADHD-Norge*. Fifteen issues of the magazine were analysed. Treating Stå På as a naturally-occurring data-source enables comparison between "official" stories about ADHD, and stories from the lifeworld. Since the use of expert knowledge in everyday decision making is a theme in how parents are seen to do parenting, the association newsletter represented both an document coming from an official source, as well as one reflecting members' own journeys.

Analysis and methodological approach

Data collection, choice of interpretation method, and actual research aims are dependent on each other (Silverman 2006). The research design steered the work towards that which was available in the data: narratives, which are a rich form of data about how social phenomena are interpreted in the 'lifeworld' (Schutz in Scott 1995); and discourses, which are representations of social phenomena generated at the institutional level. Analysing talk as narrative and text as discourse enabled a certain view into the phenomenon of ADHD parenting, where the individual can be seen in relationship to the system (Blaikie 2000).

Discourses are the pre-existing set of powerful ideas and representations, that can seem to capture people; but which "*can also be seen as a discursive or interpretive* repertoire" (Sandberg 2008: 50). They can be seen as unidirectional; limiting individuals in what we can think and say, as they stream out from institutions and to speakers mouths. Individuals are their captives. As we speak, we use recognisable portrayals of phenomena, recognisable images; as the topic or the stakes shift, we may begin to contradict ourselves, unwittingly, as another discourse is called upon, with its ensuing rules and ideas (Laclau and Mouffe 2001; Foucault 2002 [1972]). What particularly alerts us to discourses is when something seems noticeably to be 'speaking through' people, and secondly that there is inconsistency and contradiction in what they are saying (even when we understand 'intuitively' how what they

are saying is *not* contradictory, because it is a familiar part of the thickly textured everyday sense-making we all use). An example of this is how informants might say how successful they have been despite their extra burdens, yet on the other hand portray themselves as the victim. Discourse posits the individual as a subject whose speech is limited to, or hijacked by, discourses rooted in and empowered by social institutions. This is a useful sensitizing and analytical concept that points to the probable recognisability of the elements people use in representation. It is somewhat deterministic in that it reduces language-use to parameters set by our understanding of institutions and raises the critical-dialectical question of what kind of relationship is possible in the public sphere between agents and institutions (Scott 1995, chapter 10).

This research needed an additional concept to generate practical understanding and capture the lived experience and negotiations of the lifeworld. Narrative is a term that can be taken to mean both the stories people actually tell, as well as the culturally-given and recognisable representations they have at hand. *Narratives analysis* is a blurred genre that lends itself to interpreting discourses and tropes within the narratives (Riessman 1993). An important aspect of the narrative analysis is sensitivity to narrative's sense-making and meaning-making power. Unifying a series of events into a coherent narrative has healing potential; events become plotted by meaning-giving stories (Becker 1997, Ricoeur 1980).

The semi-structured interview and the relationship between the interviewer and interviewee created a setting that enabled the interviewer to take an active-listening approach, reflecting ideas back to the interviewee; in turn, themes that were important in the interviewees' lives were allowed to come to the researcher's attention. So, although the researcher steered the interviews towards certain themes, the interviewees' were given a lot of space to tell their stories. This is associated with symbolic interactionism, where the researcher is encouraged to 'put themselves in their shoes' (Wallace and Wolf 2006: 227). Conversation analysis is one of the methodological tools appropriate to this approach. The inclusion analysis of sequences, pauses, gestures, and the elements that make up a conversation in addition to the actual words spoken has opened up meaning held in the interview that can be lost in transcription (Pomerantz and Fehr 2003, Silverman 2006). The interviewee's have been cited in Norwegian, to retain the untranslatable and the integrity of what the interviewees wanted to say; and discussed in English.

This project seeks to understand how the diagnosis is understood and adapted into the lifeworld, by gathering the discourses and narrative representations used by the interviewees. The ADHD diagnosis is the basis of the Association's group "we"; thus to some extent

redefines daily activities and occurrences. These interviews were marked by their own experiences as sufferers themselves, not only as parents. There is consensus among the parents that ADHD is strongly genetic, with their own diagnoses confirming this for them. Interviewing is a suitable data collection technique for this project because the project is about how they relate to the diagnosis, which they regard as medical (with some exceptions), and how this fits in with their lifeworld and how it creates meaning and explanation for them. It is their interpretation and understanding of a medical diagnosis fraught with tensions because it is connected to undesirable behaviour. They are telling stories about their lives and thereby creating meaning.

At each new interview, the researcher was in a different position in understanding the interviewee's viewpoint. Meaning was created from an analytical inductive hermeneutical process of interviewing, listening to the recorded interview, transcription, and reflection, so that the researcher's understanding of the first interview was changed by the second interview, and so on (Katz in Riessman 1993; Kvale 2007). Reading 15 Stå På magazines, covering them in post-it notes and scribbling condensed meanings in their margins, made the researcher familiar with what kind of messages come through consistently from the Association; this in turn confirmed the categories emerging from the interviews.

Sensitivity to discourse as a critical concept led to a "*hermeneutics of suspicion*" (Kvale 2007: 203) not consistent with the research approach. The process of resolving how to attempt critique, do an analysis, and hear the interviewees in a way that was methodologically and ethically appropriate (without 'going native') involved a hermeneutical cycle of interpretation (Habermas in Scott 1995). Taking an eclectic approach enabled the process of working through the critical medicalisation theories which had inspired the research and been instrumental in the selection of the case. Methodology determines research outcomes. As the project developed, there was a shift from (though not a rebuke of) the "suspicious" conflict-oriented medicalisation theory which had inspired the research topic, yet was unable to adequately encompass the empirical data, towards a "put yourself in their shoes", phenomenological, symbolic-interactionist approach which was both suitable for working on the data, and more ethically satisfying.

This array of methodological decisions may seem less consistent than is the ruling methodological ideal, and typify a sort of "methodological paradox": that the fuzzy logic of research practice is a poor fit with linear presentation of data, and the unsettling effect encounters with the 'real world' can have on theoretical standpoints. But as Kvale (2007) encourages, method should not be "swept under the carpet" due to such uncertainties. Rather,

this chapter explains methodological decisions, without veiling the complexity of practicing them.

It cannot be taken for granted that others, through similar analysis, would have reliably made the same findings (Kvale 2007); nor can this study can not be said to be representative of a population. Rather, this research gives an ideographic description and analysis: in this case, actor's lived experiences of the world are most important. The selection of interviewees does not need to be a representative sample of a population because the sociological questions posed need to be answered with a data material that is sufficiently rich to saturate the analytic categories with meaning (Strauss and Corbin 1990; Kvale 2007). Further, the validity of narrative analysis rests upon stylistic persuasiveness, coherent meaning and the pragmatic use of the research (Riessman 2003: 65-68).

Limitations

While all those I met at my first meeting with a local chapter of the Norwegian ADHD association were women, I did interview one man. It was he who answered my email and volunteered to come; his wife was reluctant to be interviewed. This could be interpreted as being a deputising action; as informant Jan put it, it "*was actually really my wife you should be talking to, she is the one who had most of the problems with our son.*" (Jan, Interview 6). Jan minimised his responsibility and may have had less direct experience of handling their son's problems; yet it was apparent during the interview that his involvement was extensive, and he indicated the depth of his commitment throughout.

Finding interviewees through the ADHD Association creates selection bias. The interviewees were not in any doubt about ADHD's status as "real". By contacting people through the ADHD association, this study has in effect ruled-out selecting those who are still wondering about whether ADHD is a diagnosis they should accept.

ADHD is very topical in the mass media, as I pointed out at the presentation of my research to the local ADHD-Association chapter (see appendix 1). When an online news article about ADHD appears people talk about the parents of kids with ADHD and a range of strong, emotive views are expressed. Given this context, the appropriateness of interviews can be questioned. Interviewees could plausibly feel pressed to defend themselves. On the other hand, this is an opportunity to hear how we respond to the pre-existing representations, and how an interview develops in that context.

Another weakness with this research was the researcher's (relative) lack of Norwegian language skills. While I had designed the interview guide with the semi-structured style in

mind, most of the time I merely directed the interviewees to talk about particular topics and then encouraged them to talk at length, sometimes utilising pauses to this end. While this mostly worked to the advantage of getting rich descriptions, much of the interview with Anita (interview 7) which went for just over 120 minutes is more like an interesting lecture on factual information than a conversation. Kvale (2007) explains that interviews for academic purposes are similar to everyday conversations, except that the researcher steers the conversation.

Relationship between researcher and interviewees

The interviews are undoubtedly conducted with noticeable language impairments on the interviewer's part. The "mutual" construction of knowledge that occurs during an interview is weighted in the interviewees' favour. Even though this can be embarrassing, it is not unhelpful: the interviewees had a free rein to speak and tell their stories, and they do so with some authority. The length of the interviews also suggests that they took more time to explain things that 'should be' obvious to other native Norwegians, but which they evidently thought I may be ignorant of. Here are some examples where the researcher's foreignness is obviously referred to by the informant:

Interview 1

Anne:	Det er det vi kaller for 'knagger'. Her i Norge (ler). … Det er en skam å ha ADHD enda. Ute i samfunnet vårt.

Interview 2

Monica:	Så vi ser at den norske skolen er for dårlig, altså… Du vet at det er en veldig stor skilsmisse prosent i Norge… Foreldrene har ikke tid til barna
I:	[ja]
Monica:	[i Norge]. Det er full jobb, begge to som skal gjøre karriere og tjene masse penger og bli opptatt av materielle goder og sånn.

Interview 3

I:	Jeg har lest at i noen land kan det være et problem å få lærere til å gi tablettene til barna. (…)
Hege:	Nei, jeg tror ikke mange opplever det her i Norge.

Interview 5

Hilde:	I Norge så er vel det at når de er 5 år, kan de sette diagnosen og gi medisiner.

The reader can get an impression from these quotes of the consistency with which the researcher's foreignness was a factor in the interviewee's giving lengthy and detailed explanations.

The language barrier also slowed or even completely prevented responses from the interviewer, which can be interpreted as a cue for the other person to continue talking, or forces them to try to fill them silence because it makes them uncomfortable. In the end, parts

of the transcripts read like streams-of-consciousness; something that probably would not have happened if the interviewer had really managed to keep up with the flow.

From an ethical point of view, the researcher's relative lack of language skills might act to counterbalance the power imbalance in the interview setting: the informants are the experts. The researcher was dependent on their patience and willingness to understand. When I heard a word I did not understand, I did not always ask for clarification; rather I elected to listen to it again on the sound file and work it out later during transcription. Of course, the informants could tell I did not understand everything they said! But again, this led to re-articulation and reformulations, explanations, and more detail. Such that finally, I was pleased with the richness and depth of the interview data.

The interview guide was written at an early stage in the research process when I expected the problems encountered by interviewees (connected to schools, doctors, and personal image) to be comparable to those explicated in the English language literature. I expected to hear uncertainty and insecurity; or on the other hand, defensiveness. The surprises that ensued were used as a methodological tool for getting at the data.

Sociological imagination

'Going native' is a concept used to describe the enculturation of anthropologists to the tribe they set out to study. This is methodologically problematic as the researcher begins to uncritically accept the norms of the researched group as natural and normal, blinkering them to the historically, culturally, and structurally given nature of social reality.

This research was exposed to three main challenges concerning the 'going native' problem. The first of these was the interviewees' likeability. At the first interview, I was touched by the interviewee's warmth, patience, and willingness to explain; these characteristics turned out to be the common feature among the interviewees. I found myself increasingly wanting to defend them. This research has been interrupted by maternity leave: as my sense of life's temporality and meaning changed, so did my approach. The utility I had perceived in getting a diagnosis diminished; displaced by empathy for my interviewee's vulnerability as parents.

The second challenge was the interviewees' keen interest in what I planned to *do* with the interview data (Monica encouraged me to write a newspaper chronicle, and six of the seven asked me if they could get a copy or where they would be able to find what I had written afterwards). Anita (interview 7) even suggested how the research could be made practically useful for the Association, by enlightening readers about ADHD:

> det hadde vært fint om ei slik oppgave du har kunne fokusere på mulighetene. … [Systemet] mangler rett og slett informasjon.

This group of parents are active, well informed, and I was given the distinct impression that they would follow up on what I wrote about them. This research portrays of a part of their lives that is meaningful for them. In situations where one is first and foremost a parent, then how one is seen as going about that role is important for one's reputation and self-worth: so interviewees have a stake in how this research portrays them. The interviewees' indication that the final text would be under their surveillance was a form of discipline, and their concerns a reminder that critique could be interpreted as personal criticism.

Thirdly, the researcher's gathering of factual information about ADHD made it easier to understand the diagnosis in terms of its scientific status. Scientific facts are difficult to view critically; and scientific texts extract compliance from readers because of science's cultural role as the source of rational knowledge, and through agonistic language (Latour and Woolgar 1986).

These three forces (the researcher's sympathy, the interviewees' stake, and the convincing nature of instrumental scientific knowledge) were countered by a sociologically imaginative (Mills 1959) and critical sensitivity to the historically and culturally given nature of the development of the diagnosis, and its social role. Latour and Woolgar's (1986) 'agnostic' anthropological approach to science, and Conrad and Schneider's 'ironic stance' (Gusfield 1992) on deviance designations were also useful sources of sociological vigour. Mead's (1964) social psychology and Moi's (1999) knowledge-theoretical position (as mentioned earlier in the literature review) were important in allowing the researcher to brighten and refocus the lens to focus on social roles.

Ethical considerations

Even though the informants were participating voluntarily, becoming a research-object can be inconvenient, experienced as an invasion of privacy, and anonymity offered by the researcher is not total because despite removing obvious identifiers (such as names, dialect, certain activities, ages, and employment) other people who know them may still be able to identify them by the citations and context. While the interviewees have consented to this, and done so in the full knowledge that they could withdraw from the research at any time up until its completion, it may be that if they read what has been written about them, or reflect on how their interviews were finally used, that they might not like what they see. This is the issue of to what extent 'informed consent' can ever really be truly informed.

Kvale sets out seven stages of interview research, where ethics are considered at every stage. At the thematisation stage,

> The purpose of an interview study should, beyond the scientific value of the knowledge sought, also be considered with regard to improvement of the human situation investigated. (Kvale 2007: 111).

So in addition to basic research, a consideration is given to families with ADHD diagnoses. The study attempts to cast some light on the inter-disciplinary disagreements around ADHD. One of the premises of the research was that the interviewees could be struggling with stressful messages about their parenting abilities, and therefore aimed attempt to de-thread and uncover contradictory sets of values and ideas that arise in relation to ADHD and parenting, thereby showing that some of the difficulties they face are due to having to negotiate various social pressures (Silverman 2006). It was also thought at the outset that if this was the case, it might lead them to reflect that they could be asking for more or different help from people around them, or demanding more resources from schools or the state.

Consideration of different genres of literature on ADHD has prevented simplistic generalisations, and made the issues around ADHD complex. So, a thorough literature review has an ethical side in that it hinders simplistic moral judgements, and rather enabled a sociologically imaginative and informed analysis.

The literature on ADHD shows the problem of "bad behaviour" or ADHD is seen to have various causes. This variation is a result of looking at the problem from different viewpoints (some of which have interests to defend), or the calling upon of different values and moralities. Hence, a rhetorical analysis of interview data appears to be a prudent methodology for this project. This might employ what has been referred to as taking "*an ironic stance*" (Gusfield 1992: ix). On the other hand, research participants must be treated ethically, there has to be sensitivity to the inequalities produced by the interview situation, and the sociological task of understanding also has to be reached. An ironic stance to some issues does not require a deprecatory tone towards the informants, or any one who they could be seen as representing in some way. The fact that a medical claim is disputed from various standpoints does not mean the claimant is cavalier or immoral; we need to understand the social situation in which they act, otherwise the analysis is individualistic and, since the research participants do not have a right of reply, unfair. Importantly, by treating them as knowing their own lives and interests best and allowing myself to become emotionally enrolled to their cause, I was able to learn from the informants; even as I treated our respective realities as culturally-given and used the sociological imagination and 'toolbox' to create intellectual distance and prevent me from 'going native'.

Methodological choices have also been influenced by feminism. Where both nomothetic and ideographic traditions distance themselves from individual actors' personal sense-making (Grimen 2004; Silverman 2006), some feminist work explicitly embraces women's stories as a way of giving them a voice. Some feminists see women as silenced by research that does not give them the authority to have their views taken seriously (for example, Malacrida 2003; Carpenter and Austin 2007). "Hearing women's voices" has been identified as problematic, because of the tendency to treat stories as 'authentic' rather than culturally given (Silverman 2006). However, this research is conducted with an awareness of the pitfalls of the "romantic approach". Accordingly, in this research, emotions such as guilt are treated as a "*culturally given way of understanding the world*" (Silverman 2006: 123). The data are treated as reflecting culture and identity.

Being the subject of research could be experienced as reinforcement that there is something 'wrong' with their child or their parenting. A related ethical issue is the researcher's interest in culturally-given guilt and blame, which there is a set of questions relating to in the interview guide. Asking people about blame could imply it (this is also an issue of methodological bias because what the researcher expects to get from the interviews can be a self-fulfilling prophecy). I tried to handle the themes of guilt and blame with *tact*, and make it clear that I had researched ADHD enough to know that parents can receive undue amounts of negative attention when they have a child who is different or sick; the semi-structured interview style was flexible enough to enable this. I also tried to present the questions in a way that was giving them a chance to respond and defend themselves, or tell me how they had already done so; and this was indeed an opportunity all the informants took. I hope this ameliorates some of the aforementioned ethical problems.

A surprise that occurred during the fieldwork concerns the interview setting. While the first three interviews were at the interviewees' houses, and the fourth at a workplace lunchroom, the final three were all in small rooms at *Funksjonshemmedes felles organisasjon* (FFO). In the first three interviews, I asked many of the questions from the interview guide without first reflecting over to what degree those questions, individually or as elements of the interview process, could be perceived as having psychoanalytical characteristics. The scientific therapeutic interview is a recognisable genre of interaction, with well-known power differential between interviewer and interviewee. One of the characteristics of the genre is that the interviewer might actually *say* very little, leaving open space for the interviewee (or patient) to reflect on their own thoughts. Another characteristic is that the interviewer asks personal questions about how the patient felt during particular events, and the interviewee is

accordingly expected to divulge personal information to answer adequately and correctly. I have some previous experience as a volunteer crisis counsellor, and had assured myself prior to starting interviews of the goodwill of my "active listening" approach. The irritation of two of the at-home interviewees at some questions I interpreted on reflection as being natural defensiveness. At the third interview, there were some tears, and I probably congratulated myself on not reacting with alarm, and getting good data. The fourth interview was not recorded successfully, and I do not remember anything about this particular aspect. But the final three interviews were of a different character, and infused with a strong feel of what I now understand was the scientific-therapeutic genre: in the first two, I was the therapist; in the final interview, I became the patient. Because I interpret some personal disclosures made during this type of interview as almost inadvertent and unavoidable, I have omitted sections from all three of the final interviews: these omissions concerned those in the patient role. This has been a learning experience; I did eventually realise what probably had occurred (that is, a reproduction of the scientific-therapeutic interview genre, in parts of the interviews), even if it did not dawn on me until afterwards. It is certainly cringe-worthy in hindsight to realise I might have fancied myself for Arthur Kleinman, if only for a moment.

Bracketing

Interviews create a situation where meanings are created together (and this includes misunderstandings and disagreements). This leads to an ethical quandary: if the researcher does not raise questions during the interview, it is unfair to do so afterwards in the write-up when interviewees can not defend themselves or clarify their meaning. On the other hand, when there are straightforward differences of opinion, then it is acceptable to make the point. Such an issue occurred when parents told me about behaviours that *could* be interpreted as amphetamine side-effects, such as low appetite, not gaining weight, and repetitive or compulsive behaviours (or 'punding'). These are among the widely known effects of amphetamine use (Iversen 2006)[3]. I was surprised and baffled by how parents could simultaneously be so well informed about ADHD and stimulant treatments for it, yet appear to be ignorant of what "side-effects" stimulants have. I had expected they would tell me how they had weighed up the risks and benefits of amphetamine treatments, and often their self-presentation was different than I had expected; so I wondered if they were acting falsely

[3] Iversen develops a convincing argument against most uses of many amphetamines, with the specific exception of ADHD treatment.
Iversen, L. (2006). Speed, Ecstasy, Ritalin: The Science of Amphetamines. Oxford, Oxford University Press.

naïve. This was an opinion I bracketed during the interviews; not only because the issue made me slightly uncomfortable or because I am from a foreign culture, but also because my role was a sociologist, not a judge. Further on, the general topic of amphetamine-related controversy is discussed in terms of how people identify with the diagnosis. I think this is done fairly.

Further reflections on the interview process and circumstances are included in the presentation of the data.

4. MORAL ABSOLUTION

Having considered the methods and methodological issues, we are ready to look at how the empirical data from the interviews and Stå På can be interpreted, with sensitivity to the theoretical issues raised in the first chapter. This includes consideration of the 'bright side' of being diagnosed (Conrad and Schneider 1992, Solvang 2007).

Something to hang your hat on

Diagnosis is an important *status passage*. Jan's story was that until a few years ago, the problem his family had been dealing with was their son's drug problem. He was a drug addict for over 15 years, dependent on social services for a place to live and his family for food, and tended to call on his father in the middle of the night to provide transportation. I asked how getting a diagnosis for their adult son had changed their relationship:

> Jan: [Forholdet] har forandret seg mye egentlig. Det har med at før var han aktiv narkoman… Nå har han kommet over i den kan du si normale rekke på de fleste vis. Hva som er årsak og hva som er virkning, det er litt vanskelig å si her. Men vi er egentlig (.) alle sammen (.) veldig glad for at han har fått en diagnose å henge hatten på i forhold til de [rus] problemer han har hatt, og at det er verken dårlig oppdragelse eller dårlig anlegg hos han som er årsak. Det er noe som verken han eller vi har hatt mulighet til å ha styring over. Det gjøre det litt lettere, og det gjøre det også litt lettere å samarbeide med han.

The diagnosis changed their relationship greatly because it their son became more normal after getting diagnosed, and it was proof that neither the individual nor the family raising him was to blame for a drug problem, even though Jan was not certain if his son's ADHD had caused him to become a drug addict, or if years of hard living had caused the ADHD. The *doubt* around the diagnosis was to what extent it was valid retrospectively (not whether it was valid currently); but after expressing doubt about ADHD's role in the drug use, Jan says, "*But we are actually (pause) all of us (pause) very happy he got a diagnosis to hang his hat on regarding the drug problems he has had*". The pauses in speech act to emphasise the clause 'all of us' – so Jan is speaking for the entire family; bringing attention to the shared stigma of drug addiction in a family; and the shared relief of a diagnosis. Jan continues, "*It was neither poor upbringing nor bad hardwiring on his part that was the cause. None of us could have controlled it.*" This tells of the moral absolution that came with a diagnosis. It has been also been liberating to get drug problems explained by ADHD, "*It makes it a bit easier, and it also makes it easier to work with him.*" After 15 years of looking after an adult with a drug problem who had "*always been a loser*", the increased self-control and independence his son got, combined with moral absolution and liberation, has been positive – despite doubt about

cause and effect. This combination of relief and doubt resonated with a story from Stå På, in a story by a mother considering medicating in light of future scary, risky behaviours:

> Symptomene til sønnen min ble hektet på knaggen 'Skillsmisse og Samspillsproblemer i Familien'. Man kan jo spørre seg om hva som kom først: samspillsproblemene, skilsmissen eller ADHD-en? …Uten behandling ville sønnen min kunne ende opp som rusmisbruker eller kriminell. Det var skremmende lesing. Jeg sto maktesløs, og uten det nødvendige redskapet til å hjelpe sønnen min: En diagnose. (Stå På 2005, 4, p.12-13)

In spite of doubts about cause and effect, the diagnosis was the tool she needed to pragmatically help her son and to move the categorisation of their problems out of the "problems in the family" basket – simultaneously, the author is suggesting that perhaps divorce and interaction problems were caused by her son's ADHD. The diagnosis was a necessity to get attention off their living situation, and give access to the therapies that would save him from risks. In this instance the diagnosis is a case of moral absolution for the parents and illness for the child.

Among the positive aspects of medicalisation, is that a diagnosis can be used to create acceptance. Monica, whose son got diagnosed with ADD and has compulsive behaviours, put it this way:

> Så lenge moren er glad i sine barn og sier det, så tror jeg man kommer veldig langt med det. …Og på en måte - en romslig - når du vet at det er noe, at barnet har ADHD, så plutselig utvider man grensene til hva man tolererer og aksepterer. …[Man] overser litt… [og] fokuserer på det som er positivt, og det skal gå så bra. Skryter, "*Å så flott at du fikk 6 på den matte prøven!*", så alle de 2-erne veier ikke. "*Nei, vi tenker ikke så mye på <u>de</u>. Å du er så flink til <u>det</u>. Kjempebra!*"

While Monica does love her child and holds that this is the basic requirement for a mother (here and elsewhere in the interview), the diagnosis was used to give direction in areas where she might otherwise have been stricter or responded with anger. The diagnosis moved the boundaries of what behaviour needed disciplining (in this case, a compulsive behaviour that is inconvenient for others in the household and poor grades in most subjects at school). A household conflict is avoided. The diagnosis created more room for understanding and acceptance of problems, so they would focus instead on her son's strengths.

Getting diagnosed also allowed the adults interviewed to create a similar space for acceptance towards themselves:

> I: Har [diagnosen] forklart veldig mye i livet ditt?
> Anne: Ja. Jeg har begynt å forstå hvorfor ting har vært som de har vært. Ja, en forklaring, på en måte.

Since getting the diagnosis, Anne is 'beginning to understand': getting the diagnosis has raised a consciousness of her problems. Anne distances herself from resting entirely on "*yes, it is an explanation*", by adding, "*in a way*". She is indicating subtleties and partialness of exactly what the diagnosis can explain. This resonates with a view put forward in the magazine, "*It is not an easy excuse, but an explanation and a clarification*". (Stå På 2005, 4, 36) Subtleties are necessary because it is difficult to untangle the acceptable benefits of moral liberation from the

unacceptable benefits of an excuse. The topic was difficult for Jan to talk about without being misunderstood:

Jan: Jeg har det vanskelig å komme ut om dette til hans mor (.) men jeg sitter med en liten følelse av at etter at han fikk diagnosen, og fikk vite hva den inneholder, og har blitt så å si sinnsyk, så har han blitt mer hjelpeløs på det praktiske planet. Og det går spesielt på dette med å holde orden i leiligheten og ta seg av renholdet. (.) For, altså, det er noe som (.) det er en litt stygg tanke. (.) den går ut på at, "*Ja, han har fått vite at han har ADHD, og de som har det, de har nokså vanskelig med det der å holde orden.*" …Og jeg synes dette har blitt mer markert hos vår sønn etter at han fikk diagnosen. Det så jo ut som et bombenedslag hos han tidligere også, men så kunne han ta seg sammen en gang i mellom, og ta å rydde opp og gjøre rent. Men nå! Nå når det blir fælt, så ringer han til sin mor og bestiller rydde- og vaskehjelp. Så går vi der begge to en formiddag mens han er ute, og hun rydder klær og hva nå ellers som ligger slengt overalt på gulvet og på badet og skittentøysskapet og det hele, og rydde og vasker kjøkkenet.

Hesitatingly to begin with, Jan admits an "*ugly thought*" about one change for the worse in his son after getting diagnosed with ADHD and finding out what the diagnosis covers: helplessness over cleaning his apartment. Now that Jan's son is "*in a manner of speaking, mentally ill*" and has learnt that problems keeping things in order is a 'symptom', he appears both less capable of ever doing housework, and more willing to ring his mother to do it for him. The interviewer took this as an opening to agree that ADHD is used as *an excuse*, saying in reply:

I: Det var jammen sant veldig snilt av dere. Kan jeg med andre ord si at han bruker ADHD diagnosen sin som en unnskyldning?
Jan: [Ja altså]
I: [eller]

But this almost sarcastic reply and a direct question about using his diagnosis as an excuse were too un-nuanced for the interviewee's comfort:

Jan: Jeg har gått rundt og undret meg (.) litt (.) om han bruker, etter at han har fått denne diagnosen, den som en slags sovepute og unnskyldning for at han roter og et grunnlag for å be sin mor om hjelp… Så altså, jeg har en liten som jævel som sitter bak i der og sier at, "*Kanskje han bruker diagnosen for å kunne bruke oss til den praktiske opprydningen og renholdet.*" Men det er med relativt lange mellomrom at spørsmålene kommer.

Jan puts forward his uncertainty over his position by saying it is something he "*has wondered about, a little*." He reiterates the uncharitable nature of his position, by portraying himself as having a little devil on his shoulder who is nastily suggesting their son uses the diagnosis as a basis for pressuring his mother for help with house cleaning. Further, he defends their son by saying, "*The requests do come at relatively long intervals*". Jan is careful that his vague suspicion of an excuse not be used by the researcher as an allegation of an excuse. A few minutes later, the topic of housework reappeared in the conversation, this time about women in the Association:

Jan: …Det er en del av disse mødrene som sier at der de bor der ser det ut som et bombenedslag, selv om de har barn som de har ansvar for og skal prøve å ordne opp med. Men å holde orden i leilighetene sine, det klarer de ikke.

Jan suggests that houses could be untidy because of having children in them, and shows scepticism towards the mothers not managing to keep the house in order. The researcher pointed out how immaculate the houses she had visited had been:

I: Ja det er et interessant tema for jeg har jo vært hjemme på besøk til noe som har diagnosen, har barn med ADHD og diagnosen selv, og de sier at de har vansker. Men husene er utrolig rent. Jeg syntes de hadde mye bedre kontroll på det enn for eksempel det jeg har hjemme.

The researcher indirectly questioned the assertion that people with ADHD have trouble keeping thing in order, which Jan countered with, "*Ja, men det går også an å lære seg teknikker på de tingene der*." That is, tidy houses cannot be taken as evidence that people do not have ADHD; rather, that they manage it effectively. The problem for Jan may be that his son has not considered learning these techniques! "*Jeg vet ikke! Jeg vet ikke. Jeg synes det lyder litt søkt også! (ler)*" Jan finally takes an equivocating position from where he can both be morally relieved by the diagnosis and be annoyed at his son's bad habits. As a father, Jan may not have the same interest in getting a diagnosis that mothers have previously been theorised to have, and initiates criticism of an aspect of ADHD's lifeworld interpretation. Nonetheless, the interviewer's suggestion that their houses were very clean (that is, lacking visible ADHD symptoms, and arguably therefore lacking ADHD) is rebutted. In this way, Jan supports his fellow Association members, and supports their claim to ADHD - even though he may hold some reservations about that particular aspect of the diagnosis's lifeworld interpretation.

In the literature review we saw how medicalisation has been theorised to enable a morally dubious use of the sick role's "secondary benefits", to be absolved of responsibility. One could expect the interviewees to use the interview setting as an opportunity to excuse themselves from some of the responsibility directed at parents for their children's problems, and that they would report experiencing their child's diagnosis with relief. This resulted in what can be interpreted as a charge-rebuttal in the interview dialogues (Silverman 2006). Here is an extract from the interview with Hege, who has two children with ADHD:

I: Så… det var en lettelse for dere å få diagnosen og?

Hege: En lettelse, men stor sorg, også. Du blir lei deg, du blir… på en måte, ikke *skuffet*, men du kjenner deg borti det der, "*Hvorfor skal dette berøre oss? Hvorfor skal vi, på en måte, ha ansvar for to?*" Vi føler jo oss utenfor i forhold til de andre, igjen, de som på en måte kan fungere greit i sosiale samlinger. Så, ja, det er en lettelse å vite, "*Ja vi har vært i dette*". Men det er vondt, det også. (.) Ja, det er ikke (.) Det sliter. På alle.

The diagnosis brought them a different understanding of their experiences, but at the same time she points out that acknowledging the ADHD is painful and wearing in its own way. Hege uses the stigmatising aspect of the diagnosis to rebut the suggestion of being primarily motivated by moral relief: Hege's family is treated with suspicion because of how her boys

behave, and because they have a diagnosis which they have been open about. Hege explained how she and her husband often have to give instructions to their children over 'silly things' when they are out in the yard, repeatedly. "*Alt må repeteres. Og repeteres og repeteres og repeteres!*" The neighbours are in earshot and know Hege's boys need extra following-up, and have rejected them: she is certain they have banned their children from playing with hers, although they have not said it outright to her.

The interviewees told the interviewer how their children were different from other children. Their children were very difficult, lonely, agitated, angry, suffering, had insomnia and failed to thrive despite their parents' dedication and love. Experts agreed. Through PPT (school psychological service), BUP (children's psychiatric service), the Children's Policlinic and both General Practitioners and specialist doctors, parents heard that they were not worrying unnecessarily: their child was struck with ADD/ADHD, and their child did need extra help. Problems socialising with peers is common for people with ADHD, and none of the interviewees had thought their children fitted in well at schools – at least, not before getting medicated. All the interviewees had a painful story about ongoing daily problems, insomnia, bullying and traumatic incidents that had led up to the assessment process; Hilde's son had received death-threats from the father of a school peer. The children struggled with the classroom both as a learning environment and a social environment. The children's social rejection is anguishing for their parents to watch, and together with learning difficulties is a driver for parents to act, and do something to help. As an adult with ADHD reflects in Stå På,

> De andre ertet meg… Jeg var hudløs. Uten filter… En liten bagatell ble for meg en stor katastrofe. Jeg kunne leses som en åpen bok. Slike barn er det gøy å erte. Ikke sant? (Stå På 2005, 4, 24)

Rejection and inclusion are an understandably hot topic for parents. In some cases, difference is central to how parents think of their children and how the children appear to see themselves:

Hege: [Han liker spesialskolen sin]… For han vet jo at han er annerledes og han vet jo at han sliter. Vet at det ville være veldig vanskelig å komme tilbake til den klassen han gikk i før.

Hege's son knows he is different and cannot go back. Monica's son has also started at a private school, and is relieved not to go to the local state school. It is liberating to be away from the people he did not like:

Monica: Han kom jo inn på fylkes.... Han ville ikke gå der, det er veldig vide (.) flerkulturelt. Veldig mange problemer. Så i vårt tilfelle er det veldig bra at han kommer inn på den private skolen. Der var det få å forholde seg til. …Det kunne har gått så mye verre hadde han gått inn på [fylkesskolen]… Han var ikke motivert for det heller. …Han opplevde litt erting og mobbing, og så hadde han en kamerat som hadde vært mobbet på biblioteket, "*Er dere homo?*" og litt sånn. Så han var – nei. Der ville han ikke ha gått, hvor det var så mange sånne.

I: Han er reservert og kjenner…

Monica: Ja han orker ikke å forholde seg til så mange.

Monica's son's reservations towards people or places that mock him are validated by his ADD diagnosis. Difficulties socialising that could be attributed to cultural differences and social stratification (where the setting is a large and multicultural high-school), are instead reduced to an individual's limitations in relating to and dealing with a range of people.

How medicalisation occurs is outlined by Conrad and Schneider (1992) as a process involving many actors and stages. Informed "lay people" are active in medicalising their problems, foremost by presenting them to their doctors to be regarded medically. However, school and behavioural experts (the PPT and BUP), do not easily accept parents' reports about problem behaviour. According to the interviewees, there was tendency to downplay misbehaviour as "normal". This was cause for some consternation:

> Anne: [Når jeg] ringte Barnevernstjenesten og fortalte hvordan vi hadde det fikk jeg stadig høre, "*Ja jeg forstår hva du mener fordi jeg har et barn på samme alder*," men poenget var jo det at hun forstod ingenting. Fordi hun hadde ikke et barn med den atferden… og de startproblemene som min unge har (.) eller hadde. Sånn at hun har ikke skjønt noen ting! Jeg måtte jo rett og slett true med å si opp avtalen som fostermor (.) før vi begynte på legemidler.

The woman working at the Child Protection Services who Anne rang to for help, was not "wise" (Goffman 1963: 43) to the difference between behaviour of children at a certain age, and behaviour of children with ADHD. Before getting the diagnosis and starting her child on medication, Anne had threatened to give up the (adoptive) child altogether: by revealing this 'shocking' news, Anne is illustrating both how extreme and abnormal the child's behaviour was, and the tactics she was forced to use in her desperate fight to be taken seriously by the helping professionals. Diagnosis and medication marked an important passage from downplayed, unacceptable behaviour through to a mother being heard rightly. Isaksson et alia also mention this topic regarding parents encountering scepticism towards the diagnosis from teachers (Isaksson, Lindqvist et al. In press). The everyday familiarity of the symptoms can make it easy to disbelieve parents who are convinced their child is suffering unacceptably:

> Hege: Når [min sønn] begynte utredningen så sa de til meg at, "*Det er ingen ting i veien med han, han funger kjempefint*" og jeg sto på mitt og sa, "*Nei, han gjør ikke det.*" …Vi har blitt tatt alvorlig av både PPT og BUP og på nevro-teamet. Skolen er vel den instansen jeg føler at ikke har lyttet, og barnehagen. Jeg føler vi ikke hadde støtte. Det er det som er tyngst, fordi det er de som overser mest av guttene dine og du føler på en måte; "*Er det bare jeg som har vansker? Eller at de ikke klarer å se han.*" Så, det var en seier, på en måte, for meg når jeg kunne gå bort til dem og si, "*Nei vet du hva? Jeg hadde rett i de tingene, og sånn kom det ut når jeg fikk folk som hadde virkelig kompetanse til å sjekke opp i det.*" Og sånn har jeg gjort fordi jeg har ikke skullet få en diagnose på ungene mine, men jeg har følt at de skal få den riktige hjelpen.

At the beginning of the assessment, Hege had to insist that something was troubling her sons, because it was not immediately visible; though soon enough the psychological and neurological experts took them seriously. She was more frustrated by the school and kindergarten staff, and they even made her doubt herself. But Hege 'stuck to her guns', such that when the diagnosis was given it was something of a personal triumph! The medical

experts agreed with her, and they were the ones whose 'turf' ADHD is on. The authority of people who "*really had the competence*" to carry out the assessment is evoked, and the superiority and finality of qualified medical interpretations is implied over the views of day-care workers and school teachers. Hege defends her morality by arguing the pragmatic utility of getting an assessment and diagnosis for her sons: she did it to get them *the right help*, not for the sake of the diagnosis. This experience seemed so consistent with the literature on medicalisation that I continued the thread in the next interview, asking Nina directly about the relief the diagnosis offered in vindicating people in that way. Nina stopped me bluntly with, "*Det er ikke noe kjekt å få en diagnose.*"

This is an important point, because it concerns both a process where the motivating aspects of medicalisation can seem petty. We could rush to interpret Hege as primarily concerned with being right in a disagreement, and this would overshadow the driving motivation behind her actions: Hege's conviction that there was something wrong – although she did not know what it was – and that her sons needed help.

Anita discussed how difficult it is to 'face up' to problems in a diagnostic form:

> Det er ikke alltid lett å innrømme at en har problemer, eller hva som er problemet. Men en må tørre å sette ord på problemet. Og gjør man det, så er det mulighet for å få hjelp.

Further to this, Anita thinks many people prefer to over-look problems in their family that could be psychiatric. It is shameful to be diagnosed, but sometimes a practical necessity (she argues). Jan reflected on the difficulties the Association has in getting people with the diagnosis to 'come out', and explained, "*Denne diagnosen er i den aller høyeste grad stigmatiserende.*" The personal gain that parents can get from 'achieving' the diagnosis for their children and/or themselves is strongly tempered by the stigma they acquire, and the personal nature of the investigations carried out during assessment. Nina explained that when children have problems in schools and kindergartens, their parent get assessed by the PPT:

> You get observed by them. They watch you with your child and record it on video, to see how you interact. They want to rule out every other possible cause of behavioural disturbance before they give an ADHD diagnosis.

Although Nina agrees they diagnose rigorously and rule out other causes, she personally was not subject to this, "*Det trenger ikke du, sa de*". Nina, who works in a specialist occupation, thinks she was exempted from any humiliations because of her assertive approach and ability to formulate her views academically, "*In their language*". But she knows of others who have had their parenting evaluated, their houses inspected, and felt humiliated by it. So, she told the researcher clearly that not all parents meet with "the experts" on the same terms.

By contrast to Nina's experience, it took 2 ½ years before Hilde's son was assessed. Rather, her mothering was the focus of attention:

Hilde: En uke før han fylte 5 år begynte vi å gi han medisiner. Oppe i den prosessen fra han var 3 til 5 så måtte jeg gjennom alle mulige foreldrekurs, fordi at først var det bare det at det var meg som ikke var flink nok. Jeg var ikke konsekvent, jeg var ikke flink nok til å følge han opp.

I: Hvem fikk du den beskjeden fra?

Hilde: Barnevernstjenesten. Fordi det var de jeg tok kontakt med. …Jeg husker at det var mange kamper. Første skulle jeg gjennom mange foreldrekurs, med filmer hjemme, og jeg fikk støtte fra hun som filmet hjemme: "*Du gjøre det rett! Han klarer ikke sitte i ro, dette her er -*" Ja. Og det hjalp jo på, til at han kunne bli utredet. Men det var mange (.) det var en stund da jeg følte meg totalt mislykket som mor på grunn av at det var det som var fokuset… Det var ikke lett å få han utredet. Det var kampen lik.

Before her son got diagnosed, Hilde was seen as the source of his problems. "*I wasn't good enough. I wasn't consistent; I wasn't good enough at following him up.*" Hilde was careful to point out that it was her who made contact with the Child Support Agency in the first place, not visa versa, and Hilde had many 'fights' or 'battles' with them on the way to getting her son assessed. It was not until she had been through a series of courses and was filmed interacting with him at her home that it was eventually confirmed that she was doing what she should, and that her son was allowed access to an assessment.

Behaviour such as being aggressive at birthday parties, provoking death-threats from other children's parents, or driving parents to distraction in front of the neighbours is challenging in itself. However, the stigma of ADHD is not limited to actual behaviour, but also includes the 'dangerous' image of the disease. For instance, Monica had to insist that the private school take her son, despite his ADD. The principal had not wanted a problem student. Monica told me how she had to ring the principal, and explain the difference between ADD and ADHD, that her son was doing well on medication, and that he deserved a chance.

Norwegian women are in a somewhat different situation than Malacrida or Singh's mothers when it comes to their gender role and family responsibilities. Although the data are too limited to make generalisations, the interviewees' confident stance could be interpreted as indicative of a feminist-influenced cultural setting where neo-conservative imaginations of women and motherhood do not hold the same validity. The seven interviews all expected help for their children, and felt fully entitled to claim it. They do not present themselves during the interviews as "feeling guilty", nor do they seem afraid *not* to "play along" with the "helping professionals" (Malacrida 2003). Rather, the people interviewed for this research confidently and righteously demand services they believe the diagnosis should entitle them to, but which are not always forthcoming. Hilde explained how her relationship with pedagogical assistants changed after she got her own diagnosis and starting taking Ritalin:

Hilde: Før hadde vi mye kontakt med lærerne og assistentene, som var veldig positivt. Men etter at jeg begynte å lese mer om lover og regler så ble jeg for sterk for dem. For de kan ikke avfeie meg lenger, så de trekker seg unna. …Etter at jeg begynte på medisiner, […sluker jeg] alt som jeg kommer over av fagstoff og lover og paragrafer, og får med meg alt. For det at jeg klarer å sitte… Det er nok det som er

> avgjørende. Også klarer jeg å få skrive det, så de får skriftlige klager. Det liker de ikke… Jeg skremmer dem nok litt.

Empowered by Ritalin, Hilde now takes a legal approach to her son's education and the help he is legally entitled to. Hilde has "*become too strong for [teachers and assistants]*", and they can no longer 'brush her aside'. She writes written complaints and admits that she probably scares her son's teachers a little bit. Hilde shows her knowledge and capacity for action, "*I read all the academic literature, laws and [legal] paragraphs I can get.*" In Norway, children who require help that they are entitled to under a particular legal paragraph (see footnote 3 on page 17) are sometimes referred to as 'paragraph 6' or 'paragraph 8' children. Hilde's son is a 'paragraph' child, as his mother boldly reminds his school.

Nina does not have ADHD herself, but was once explicitly blamed for her child's problems. When her son was in pre-school, a new pre-school teacher whom she described as "*young, freshly graduated, and without children*" rebuked her for the way she dealt with her him. Nina was so insulted by this that she responded by printing the relevant paragraphs of the Child Protection law, which she already knew was publicly available online, and went through them point by point with the pre-school teacher's superiors. The dispute was settled by the teacher being reprimanded and relocated. As Nina put it, "*Jeg er ikke akkurat ressurssvak*".

It also appeared that the process of meeting others having similar experiences was an important condition for building confidence and consciousness. Hege talked about her need to talk to other people about the diagnosis and to meet people in the same situation, and participate in various activities arranged by the Association. For mothers like Hege (with and without the diagnosis themselves), the diagnosis provides a rallying point to meet up with people dealing with similar challenges and share their experiences. The data can be plausibly read as pointing to the contingent nature of what a diagnosis means. It seems that for the Norwegians who were interviewed, it was a group process in a particular cultural and discursive setting that made them feel confident.

Malacrida (2003) wrote about how mothers' worries are ignored, while at the same time children's problems are blamed on them. Interviewees in this study did express satisfaction when they could approach the school with their child's diagnosis, or the relevant legal paragraphs. However, the suggestion that a diagnosis is merely a route to moral

absolution for the parents, seemed implausible after talking to people who ADHD actually concerns. The hermeneutics of suspicion would lead one to criticise that this is exactly what they want us to think, because it benefits them by making them look innocent even though guilty of something. This is precisely Malacrida's point. Further, it should be pointed out that the diagnosis ADHD is stigma laden, and that it's strongly genetic nature makes it a taint on their family, parents especially. They have their ways of dealing with this (various ways of defending their family's standing and morality, and focussing on ADHD's positive side for what its worth), as discussed further on.

A diagnosis or medical condition can become part of a person's identity. ADHD gets its particular social meaning through the work people do on it in relation to their own situation – and in the case of ADHD, from the perspective of people with the diagnosis and their near family members, their interpretations create meaning about their family member's challenges and successes over generations, as well as creating meaning about the current situation. In this sense, because of the emphasis on the biological nature of ADHD, a whole family gets the diagnosis.

Conflicting moralities

Expert opinions are not always sufficient to legitimate an act, or defend a reputation. Whether supported by expert systems or not, there are still strong norms operating against medicating. To elaborate on this, I would assert that the anti-tablet taking culture is similar to the values held by those in the abstinence movement. Not drinking and not taking pills are associated in some ways, and there is some overlap in how each is perceived. Being a non-drinker or a non-pill-taker is both an action and in some contexts, a moral status [see appendix 6 for an example of this; and Stå På (2009, 1, 22) asserts that it is a myth that all people with ADHD even use medications]. As with alcohol, pill-taking is associated with ignoring or glossing-over problems that one "should" face up to. Using alcohol, drugs, or pills is seen by some as a temporary and unworthy method of dealing with life's difficulties. The main complaint of the anti-"lifestyle drugs" movement is that the human condition becomes a medical condition. Self-knowledge and insight, and cathartic expression, is lost to the blandness offered by for instance Prozac: one might lose one's demons, but lose one's angels, too. Unhappiness that is caused socially (for example, oppression) is fixed by neutering individual's feelings, rather than addressing the cause. Additionally, we are informed about the pills in the first place by the industry which is selling them to us for their profit. So we see there are a number of morally loaded reasons not to take pills: lost self-knowledge and expressions thereof, lost

opportunity for social change, industry creating a false need for their product which we then literally swallow, and more diffuse reasons connected to 'good taste'. Klerman coined the term "*pharmacological Calvinism*", to refer to:

> a belief system in which drug use is held to be bad and potentially even dangerous if its makes you feel good. A drug that makes a subject feel good either is somehow morally wrong or is going to be paid for with dependence, liver damage, chromosomal change, or some other form of secular theological retribution. Following up this lead, an NIMH study in the early 1970s found that many lay people viewed nervous problems as a sign of moral weakness and the use of something like tranquilizers for such difficulties as further evidence of weakness. (Healy 1997: 227).

The Norwegian state church is Lutheran, not Calvinist, and many Norwegians emphasise a cultural relationship to the church, rather than a religious/spiritual one. So while 'Calvinism' might not be the appropriate label, nonetheless, the implied moral weakness of needing medication is attended to by Monica, when she says:

> Vi kommer fra et veldig sterkt kristent hjem og min mor var hjemme og var veldig sånn, "Alkohol? *Nei*. *Ikke*." Min far, han fikk ikke Clausthaler en gang! Ikke inn i vårt hus. Min mor var sånn. Veldig streng på det. Så jeg er oppdratt til at man skal holde seg unna alkohol, eller rusmidler, da.

By mentioning her own mother's abstinence and strict religious stance on alcohol, Monica was invoking a moral code associated with the Norwegian Lutheran church, and calling upon it to demonstrate her own responsibility. She makes a parallel between drugs and alcohol. The sub-text of what she was saying was that they *are not an immoral family* who would take pills for an easy solution to life's difficulties. Monica continues with:

> Men det er så viktig å få fanget opp og få diagnosen. Da har man ikke det behovet for å selvmedisinere seg. Og det har jeg lest mye om også. …[Hvis man] må ruse seg så blir det så ekstra vanskelig.

She approved of her son's amphetamine treatment because it would protect him from drug experimentation and addiction; Monica strengthens her credibility by asserting, "*And I've read a lot about this, too*". Further on in the interview, the interviewer pointed out that the issue of people 'self-medicating' because they have untreated ADHD has been in the mass media, and that others think they are 'merely' drug addicts looking for easy (immoral) access to drugs. Then Monica was asked what she thought about the drugs they want being the same medication as is used to treat ADHD:

> Monica: Ja, altså, jeg er <u>så glad</u> for at min sønn fikk diagnosen da han var 11 år. For da er jeg veldig trygg på at han ikke vil begynne å søke rus. …Vi ser jo det på hun datteren vår, at det er veldig mye alkoholbruk. Så vi har bekymret oss for det. Sånn at, (sukk) nå har ikke mine tre voksne brødre (…) fått diagnosen eller de har i hvert fall ikke fortalt det til meg. Men to av de har, det er et stort alkoholforbruk. Og jeg er helt overbevisst om at får barna eller får man diagnosen og får man medisiner så kan man bli *reddet* fra å bli en rusmisbruker. Jeg er helt overbevist, etter alt jeg har lest. Så det er så viktig å bli fanget opp i systemet, få diagnosen, hvis man har det, og får hjelp. Jeg vet en annet tilfelle om en mann i 20-årene som er <u>helt</u> på kjøret… har ikke fått diagnosen men det er helt tydelig at det er ADHD. Så derfor er jeg så opptatt av at de må få diagnosen <u>før</u> puberteten. For å unngå. Fordi stoff bli så spennende.
> …Og i gamle dagene var det ikke narkotika, da. (…) det er helt klart at før var det alkohol. Så [brødrene mine] brukte det.

Monica is not only pleased that her son got the diagnosis early, but convinced –after everything she has read- that early diagnosis saves people from becoming drug and alcohol abusers. Monica used three anecdotes (about her daughter; and a young man she knows who has 'gone off the tracks'; and two of her three brothers, who are heavy drinkers) as examples of people who could have benefitted from diagnosis at an early age. Their undiagnosed ADHD destined them to problems with drugs, depression and alcohol. Monica feels very confident that her son, who got an early diagnosis and is "*a very happy young man*", is safe from the problems the undiagnosed people have. Thus, a treatment that involves pill-taking is no longer seen as immoral.

Rather than 'not facing up to a problem', the medications actually help them avoid problems, because the biggest problems are seen as lying in the future when drugs and alcohol become available. Therefore, it would actually be more immoral to deny somebody medications for an illness they have been properly assessed for (Monica's caveat that it is important "*if they have it*" to get the diagnosis, distinguishes between those such as her son who can be helped by the legitimately diagnosis, and others). So the morality associated with abstinence and naturalness is interwoven by Monica with scientific expert knowledge that she has access to through reading. The scientifically documented risk-reduction offered by the "Ritalin Track" (Singh 2005) displaces other ideas about morality and how to be a good mother. Stå På supports this idea through promotion of the Association's black T-shirt that reads, "*AD/HD – back on track*" (a play on the AC/DC album, "*Back in black*").

Being against alcohol and in favour of medicating with amphetamine can be construed as contrary from a certain perspective, there are also other ways to interpret this. In this case, the morality associated with abstinence was invoked to present a respectable and careful self; that is, one who would not "drug" their child. Nina had also been reluctant to medicate, and waited a year before finally trying her son out on medication. Other informants also spoke their morality into scientific terms. It is a case of doing the best parenting possible and looking after the child's best interests, by utilising the available scientific advances. Hege is glad she was able to get her sons diagnosed, and would like to see other parents who are less able to manage, helped:

Hege: [Sønnen min] sier selv, "*Tusen takk, Mamma, for at du brydde deg og at du gjør det beste for meg*". Så jeg føler jeg har gjort en god jobb …Jeg vil tro, det er noen foreldre som sliter mer med barna sine enn andre. Foreldre som ikke klarer seg så godt, de som ikke klarer å få hjelpen til barna sine. Jeg kjenner et par gutter som jeg skjønner, jeg skulle ønske jeg kunne hjulpet de. For foreldrene klarer det faktisk ikke.

I: For de sliter sånn selv?

Hege: De sliter selv og barna vil komme til å slite mer enn foreldrene. De klarer ikke å se det selv. Og det synes jeg er litt sårt fordi det er så unødvendig. Jeg kjenner foreldre til barn som sliter kjempemye og jeg tenker, "*Hvorfor er det ikke noe hjelp?*"

Hege feels sorry for children of parents who were too tired to notice how badly their children were faring socially, or so defeated that they turned a blind eye. Hege's sons are on medication because she was attentive enough to notice they needed help, not because pills are an easy answer. When Hege sees other families struggling, she wishes she could help them – because the children's futures are so uncertain, "*[The parents] are struggling and the children are going to struggle even more.*" Hege thereby presents herself as a better parent than those who do not get their children onto the Ritalin track.

Hege had known something was wrong with her child, but the school didn't listen; she persisted and was proven right and her child *did* need help. Hege was assured she was sure she was doing what was best for her child. She thought others who criticised the diagnosis were only showing their ignorance. Nina and Anita were not only well informed, but among those who create and disseminate information. Monica, Jan, Anne and Hilde knew they were well-informed and knowledgeable, having read comprehensively on the topic: echoing Malacrida's (2003) findings. The proof that the parents had that they had been right to worry in the first place was drawn from authoritative experts.

This chapter has argued that diagnosis provides a bright-side of moral absolution, and has shown how the diagnosis is connected to a meaningful identification with the diagnosis and a belief that the diagnosis will give access to assistance. Parents' motives for acting as agents of medicalisation should be understood with compassion.

5. FATE: "I know it's not my fault, but I do ask why"

Now that we have considered the 'bright side', we now turn to consider the 'dark side' of being diagnosed. Diagnosis has a stigmatising effect, which can make the diagnosis itself into a burden in addition to the actual ADHD behaviours (Conrad and Schneider 1992, Solvang 2007).

In contrast to previous studies of mothers of children with ADHD, the mothers in this group consistently specified that *they felt themselves to be good parents*. This occurred in an interview setting where there was a set of questions relating to blame, although the question, "Do you feel guilty?" was never asked specifically (the reader is reminded that implications of guilt are cultural, as discussed in the literature review and methods section; the author does *not* imply that the parents should feel guilty about their children's behaviour or their diagnosis). Those I spoke to highlighted incidents where they had been hurt, disappointed or insulted; but at the same time as they were careful not to exaggerate. A clear message came across that while they thought staff in government services and schools meant well, that there was a lack of understanding in schools and public services of what ADHD is and what kind of assistance is helpful.

Their presentation of their mothering was free of doubts: the diagnosis let them brush aside mother-blame. But while they were careful not to present themselves as feeling as if they were bad mothers, or actually being bad mothers, questions of a more metaphysical nature did arise. Monica wondered why her family should be additionally loaded on top of all the other difficulties and constraints and challenges that they know their children will have to face:

Monica: …jeg har [ADHD] antakelig i liten grad. Jeg har aldri hatt behov for rus. Men jeg har følt den uroen, rastløsheten, og litt sånn (.) har ikke det helt bra, liksom. Jeg er ikke sånn som de andre liksom. (.) Impulsiv. Vimsete. …Men det er så viktig å få fanget opp og få diagnosen. Da har man ikke det behovet for å selvmedisinere seg. Og det har jeg lest mye om også. Og det er veldig trist, og det er ganske vanskelig (.) jeg er kristen selv (.) det er vanskelig å ha noe som gjøre livet litt ekstra strevsomt, fordi man har fått noe. Man kan ikke hjelpe for det, det er så genetisk, det er jo så arvelig. 70 til 90 prosent arvelighet. Så det kan være litt vanskelig å forholde seg til at, "*Hvorfor skal jeg få noe som er så vanskelig å leve med?*" Det er ganske tøft. Og hvorfor skal mine barn ha det strevsomt?

I: Livet er vanskelig nok fra før.

Monica: Ja det er tøft nok. Og særlig hvis man da må ruse seg så blir det så ekstra vanskelig. Jeg kjenner en uro for min eldste datter. Hun fikk jo diagnosen men hun tålte ikke Concerta. Og det er jo dumt å blande anti-depressiver og alkohol. Så man blir jo litt bekymret for sine barn, for vi er glad i dem. Hun strever veldig på det sosiale og vil ikke være med oss nå, "*Vi? Nei*". Vi har liksom gjort noe dumt så hun vil ikke være med oss. Det er veldig sårt. [ja]

I: [ja]

Monica: Så derfor er jeg så opptatt av at de må komme til behandling.

Monica explained she was an active Christian, so her view on certain problems as determined by fate or predestined could be explained by that: however, despite asserting a Christian ontology she used scientific facts about ADHD's heritability, "*One can't help it, after all [ADHD] is genetic… 70 – 90 percent heritability*", girders her claim that the individual is powerless against their ADHD through what Schick calls a 'protocol sentence' (Brown 1990). Such strong textbook-like facts strengthen the speaker's credibility (Latour and Woolgar 1986). Asking, "*Why should my children have something that makes life harder …[when] it is hard enough already[?]*" is a question used as a starting point from which to make meaning. "*Why me?*" is a meaning-creating question; it acts as a turning point from where individuals seek answers, and then go on to create a meaningful narrative (Kleinman 1988; Becker 1997). In Monica's case, her daughter's ADHD explains why she has rejected her parents; the strongly genetic nature of the diagnosis in turn explains why her daughter got it. Thus, ADHD is part of making sense of life's difficulties: it gathers a collection of otherwise diffuse and otherwise semi-articulated problems under the diagnosis (Conrad 2007). By reducing the weight of failure, our everyday living problems and living questions become clearer.

Hege did not mention religion, but she too struggled with fate. Hege's slightly despairing question, "*Why should this touch us?*" (Norwegian quotation given earlier on page 35), was connected to her sadness for the problems they have had, and concern about the risks they face in future. This fits with the idea of ADHD as a life-course risk. It is a facet in the production of meaning and reflects a feeling of being set apart from others, feeling different, isolated, and alienated. In addition to behavioural problems, their stigma - risk itself - is an "othering" force (Lupton 1999). The suffering is responded to with sense-making narratives about what ADHD is and why it has afflicted their family.

Interviewees appealed to the interviewer to acknowledge that there is a certain amount – an enormous amount – of what happens in a child's life and who that child is, that is beyond the parents' control. In this emotional context of helplessness, they were being strong and taking action. As Anne stated, "*Man må legge til rette for barnene sine, sant?*" Anne asserts that parents must facilitate for (or, set things up for) their children, and requests the interviewer's agreement at the end of her statement. She can do this because that parents have a duty to help their children is a strongly supported norm. So, ADHD is a site for intervention. ADHD provides a *vocabulary* from which parents can approach the schools about how to look after their children.

While getting an ADHD diagnosis has previously been suggested to liberate and absolve, the worry and concern the parents continue to have for their children, and the way they have to extend themselves to help them, shows how the diagnosis can be experienced more as confirmation. The mother-blame that was so prominent for Malacrida's (2003) English and Canadian mothers is displaced in this setting by *genetic fate*. *The diagnosis does not remove suffering; it puts it in to new terms of genetic fate*. While this project began with an aim of interviewing parents of children with ADHD diagnoses, it became apparent underway that in talking about their children and their parenting, the interviewees also talked about themselves and their own ADHD diagnosis, or that of extended family members. With the exception of Anne whose children are adopted, all of the interviewees talked about ADHD as familial:

> Monica: I have a low degree of ADD. [My children] get it from me. … My brothers are undiagnosed … but two of them have, there is a large consumption of alcohol.
>
> Hege: There are a few diagnoses of ADHD in the [extended] family, and the number of them is probably going to increase.
>
> Nina: My son got it from his father.
>
> Hilde: I can confirm with 99% certainty… that my father also had it.
>
> Jan: We strongly hold the opinion that he got it from his [biological] father… [who] has clear psychotic characteristics.
>
> Anita: My father had all the symptoms. He would have been diagnosed with it... I don't have ADHD but my daughter gets it from my side [of the family].

Those interviewees who did not have an ADHD diagnosis themselves (Hege, Nina, Jan and Anita) still told stories of families tending to have individuals with ADHD characteristics. These interpretations are not limited to the local Association chapter, but also occur in the Association magazine. Pernille Dysthe, writing for Stå På, explained how her son got his ADHD from her, she got it from her father, and she suggests that her grandfather who committed suicide at an elderly age probably did this because of his ADHD.

These new terms may have downsides of continuing individualization and seeming fate/inevitability:

> Anne: at det kanskje alltid vil være et eller annet, det tror jeg. Fordi jeg ser det bare på meg selv. Også jeg har jo slitt med mine ting uten å være klar over at jeg har hatt en diagnose. Jeg har stått på egne bein. Klarer meg greit, med både økonomi og utdanning, jobb – alt dette her. Men det har alltid vært noe på veien som har vært tøft å stå i. Og det tror jeg nok at de også regner med å oppleve.

In hindsight, Anne sees her own past struggles in terms of her ADHD. She expects that there 'will always be something' with her children, and that they will come up against similar challenges (although they did not inherit ADHD from her, as she is not their biological

mother). Jan, whose adult stepson has ADHD, was worried about the heritability of ADHD and implications for his beloved grandchild:

Jan: Da vi fikk høre denne her at sønnen hadde fått diagnosen, så ble vi jo unektelige nokså bekymret, for han har jo en liten sønn.
I: Og dere var redd for at [barnebarnet] skulle også få diagnosen?
Jan: Ja. Både meg og min kone tenkte jo på den muligheten.

The happiness mentioned by Jan earlier (previous chapter), which was felt by everybody involved when Jan's son got diagnosed, was tempered by the "*undeniable worry*" that accompanied the genetic understanding of ADHD. This citation shows how diagnosis on a father has possible implications for the son, because ADHD is seen as running in families.

Work on the reproduction of social inequality through the school system has pointed out that those who do well in school often come from families where it is expected to do well at school, and where parents are competent and confident with the curriculum. A student whose family background does not include familiarity with educational codes or whose identity rejects those values is set at a disadvantage (Willis 1977). However, some of the factors that sociologists consider socially determined at the macro-level and considered by the interviewees to be genetic when it concerns the individuals they are discussing.

To recapitulate, dyslexics take legal action because of the failure of their school to employ the de-stigmatising power of the diagnosis. People with ADHD are concerned are ADHD people about getting treatment and getting the right help, but they also share the concerns of these above-mentioned dyslexics who have gone to court regarding social effects of their diagnosis. The social outcomes of education are at least as important as purely educational effects. For unlike Paul Willis's (1977) school-outsiders, the children with ADHD do not have a collective to be with in school who share their situation. Furthermore, they are not deliberately sabotaging their own education. Having ADHD by definition means some kind of deviation from school norms. There is no pride, for most, in standing together in a school situation and talking about a "we" with ADHD:

Anne: Det hadde blitt så veldig mye enklere hvis ikke det hadde vært så stigmatisert, det å ha denne diagnosen. Fordi folk får problemer med å identifisere seg med diagnosen. Den blir en skam hos mange. Og det ser jo vi i organisasjonen om ADHD, at folk vil ikke være der, ungene synes det er flaut, de vil ikke komme til samlinger og møte andre i samme situasjonen, de vil ikke ha brev sendt hjem med ADHD [skiltet?] på, for eksempel. Så jeg hadde håpet at det kunne blitt litt mer alminnelig-gjort og aksepterte. Akseptert i sin helhet. For at folk skal få det bedre med seg selv.
I: OK. Jeg visste ikke det.
Anne: Ja
I: Det må skape en stor (.) utfordring for ADHD-Norge hvis de som er med i organisasjonen ikke vil møte de andre. Jeg snakker særlig om de ungene.
Anne: Ja, neimen, altså det kan være voksne også det! Sant? Det kan være at mor gjerne melder seg inn i organisasjonen fordi hun har et barn med diagnosen, men far tillater ikke at noen skal vite om at de har et barn med diagnosen, for eksempel. Det kan jo være de voksne også. Sant? (.) Det er en skam å ha ADHD (.) enda. Ute i samfunnet vårt. Det synes jeg er veldig synd. Det gjør det så mye vanskeligere

for den som har det, spesielt ungdommer tenker jeg som er gjerne i den alder hvor, ja, mange hormoner og mye som skjer. Sant? Og i tillegg så skal de ha det problemet.

I: Ja. Puberteten er vel nok uten [andre…] problem.

Anne: Ja og det synes jeg er veldig synd. Og jeg ser det her. Han tenåringen min han bryr seg ikke. Men hun jenta mi har ikke alltid lyst å si at hun har ADHD eller hvis hun har venner her og hun skal ha medisin så har ikke hun alltid lyst å vise det (.) og det er fordi hun har blitt terget på skolen. Så det, ja. Det er langt igjen å gå ennå.

Anne tells the interviewer it would be much easier without the stigma, because the children think it is embarrassing. She would like ADHD to be made more common and accepted, so that people could feel better about themselves. In response, the interviewer suggests the embarrassment applies mainly to children and young people. Anne, surprised, explains, "*It is shameful to have ADHD* (pause) *still.*" By adding, 'still', Anne indicates the possibility of progress, but "*There is a long way to go*".

Hilde's son also felt the negativity of the label:

Hilde: …Og det var som [sønnen min] sa en gang, "*Mamma jeg vil ikke ha denne diagnosen. For at jeg kommer aldri til å bli (.) godtatt. Jeg kommer alltid til å få på meg at det er meg som er så sint, og hvis jeg ikke klarer å slutte å være så sint, så kommer jeg til å havne i fengsel*". Og jeg prøvde å si, "*Vennen min det er veldig mange som klarer å slutte å være sint*". Det trodde ikke han at han kommer til å klare, for når han ser på de andre, så er de så rolige.

Hilde's son feels he will never be accepted on his own terms. He interprets his difference from other children in terms of his anger compared to their calm, and takes it as a sign that he is destined to end up in prison. Hilde told the researcher she had tried to assure him that it was not inevitable, because many other people manage to stop being angry: yet that is not what her little boy sees lying ahead. Despite the armoury of the Ritalin track and his mother's encouragement, the negative fate discourse attached to the diagnosis was prominent in how he envisaged his future.

Family stories and authenticity

As mentioned in the literature review, people are seen as placing a certain amount of trust in experts and use them as sources of reliable knowledge, particularly when matters are unclear or involve dilemmas or threats. The issue of personality or as Singh calls it, "authenticity", is often overlooked in ADHD research. The question of whether the child is their true self when medicated and behaving well, or whether the medication is unnatural and makes them someone they are not really, is left unaddressed. There is no clear way to relate to this issue presented in the scientific literature, nor in the recent pages of Stå På. In short, there is an absence of expert advice on the topic of the 'true self', and so the interviewees did not have certain answers about it. Further, the question was met with a little hostility as if it were a

very personal question; while other questions which I had thought were equally as private and personal were greeted with generous stories.

Anne: Nei det var litt vanskelig akkurat det spørsmålet synes jeg. (.) Fordi at jeg synes at det er både-og. (.) Altså, det at de har diagnosen ADHD, det blir jo en del av barnet, sånt? Og ut i fra det, så prøver jeg å se helheten av barnet. Jeg kan ikke (.) jeg kan ikke bare plukke vekk ADHD og sette den i en bås og så se på ungen på en annen måte fordi det er, den er en del av oss. (.) …Å dele det opp eller separere det fra en annen det tror jeg ikke at jeg kan. (.) For den blir også en del av personlighet.

I: (.) Ja

Anne: Men det kan hende at jeg tenker sånn fordi jeg går veldig opp i det. (.) Nei jeg tror ikke jeg kan dele det (.) nei.

This quote shows how Anne first politely told the researcher it was an undesired topic by saying, "*No, that's a bit difficult*", followed by a pause. She explains ADHD is part of the child and that they she tries to see her child holistically, continuing, "*The diagnosis becomes part of the child. I can't* (pause) *I can't just pluck the ADHD away… and see the child in another way, because it's a part of us. I can't divide it or separate it… it becomes part of our personality.*" After this taking this strong position she adds the caveat, "*Maybe I think this way because I'm so into it*" before returning to her position, "*No I don't think I can divide it [from the individual]. No.*" Experiential authority is added to Anne's position by including her view of her own diagnosis to answer the question about her child, and by strongly distancing herself from any indication that she wants to change her child. This then shows the interlocutor her dedication to and acceptance of her child.

Monica was also uncomfortable with being asked to find a metaphor, comparing ADHD to other illnesses or the experience of ADHD to other experience. First she asked a clarifying question, which was answered by giving an example from a study by Singh:

I: For eksempel, jeg har lest om en mor som synes at ADHD'en var som ville dyr i barnet hennes som hun måtte ta kontroll over. Andre mener at det ikke går an å skille mellom ADHD'en og barnets personlighet, for den er en del av hvem den er som person. (.) Hvis du skjønner

Monica: (sukker)

I: Du må ikke

Monica: Det var litt vanskelig, jeg må tenke litt. (pause 8 seconds). Nei jeg føler ikke (pause 5 seconds) Vi har jo ikke hyperaktiviteten. (pause 3 seconds) Jeg tror det er mye vanskeligere og mye mer strevsomt når man har et hyperaktivt barn. Vi har jo ADD. Så det (pause 10 seconds) Hva skal jeg si?

I: Nei det er ikke sånn du tenker.

Monica: Nei ikke så voldsomt, nei.

I: Vi dropper det.

Monica: Han, altså, min sønn, han er verdens snilleste. Han er glad i oss og vi er veldig glad i han og vi *sier* det, og vi merker bare det at han er mer utålmodig og blir lett stresset av lyder og når han ikke har hatt medisiner. Men altså. Det er veldig forskjell fra da han var barn. Før han fikk diagnosen, da var det mye mer stress. Særlig når vi skulle på landet og sånn. Hvis ikke han fikk en cola så ble han skikkelig, helt sånn "Rrr!" urolig. Det ble mye stress og kaos. Nei det er vanskelig å si. De er liksom, den de er.

As already pointed out in the methods section, the arguably inappropriately psychotherapeutic tone of the topic area and questions could be a factor in the interviewee's reluctance to answer. Language could have also played a role. Punctuated with agonising silences (broken only by baby noises), Monica made the distinction between ADD and ADHD. After the interviewer agreed to drop the topic, Monica generously covers over the discomfort and tells a story about how much she loves her son; adding that before he got the diagnosis he used to be more impatient and their life was more chaotic. So Monica refused to answer the question on the terms it was presented to her; but out of her kindness and good manners explained how her son is calmer now, and finally, "*It's difficult to say. They are who they are.*" That is, like Anne, Monica accepts her son for who he is (now that he is medicated for his own good). Any implication that medications to change behaviour change the authentic person is held away from discussion, instead bringing in ideas of love and acceptance.

Hege dodged the question by saying, "*I think ADHD is genetic. It comes from our ancestors.*" The interviewer accepted her response immediately and moved on. Nina, similarly, gave an articulate genetic-scientific explanation for ADHD and also emphasised that it was a *condition* that is part of who they are.

The interview with Hilde was one of those conducted at FFO. Perhaps because of the interview setting, Hilde was willing to discuss the question, drawing an interesting parallel to similar questions of authenticity relating to mental illness:

> Hilde: Ja den må jeg tenke litt på. (sukker) Jeg hørte en si en gang, "*Jeg har en sykdom, sykdommen er ikke meg.*" Jo, den er din personlighet. Men samtidig er det stikk motsatt, når jeg prøver å forklare til han – og til meg også – at noen av ristingene er sånn fordi du har dine - du kan ikke kalle den for en funksjonshemning for det er et sånt negativt ord for en gutt [i hans alder] – men noen av disse ting bare er sånn og du må lære å leve med det. "*Da er det bare personligheten min, da!*"
> "*Hmm nei, du kan skille personligheten og hva som styrer deg.*" (.) Ja. Jeg klarer ikke alltid å se det. Jeg ser det er utfordringer å forklare det til en unge [på hans alder]. Det er så mye mer enn det og han føler seg bare som et stort skilt. Og derfor får jeg skylden for alt. Så, der har jeg glemt spørsmålet (ler)
> I: (ler)
> Hilde: Ja men akkurat mot funksjonshemning eller ikke, eller det med personlighet, det er rett og slett kjempevanskelig.
> I: Så det er ingen klare linjer mellom de to.
> Hilde: I alle fall vanskelig å skille.

For Hilde the question was whether she and her son were 'disabled' or if it was their personality. When she tells her son it is just how it is and he has to learn to live with it, he argues that it must then be his personality. In response to her son, Hilde explains a slippery idea about the authentic self, that, "*you can make a difference between your personality and what controls you*," but admits in the interview it is difficult to see the difference.

Jan thinks it is a riddle whether it was purely genetic, or a combination of things:

> det er ikke noe bestemt ting som har påvirket han. Men det er nok den sykdommen som han har fått med sine gener, ja? Det kan jo være andre, en del ting som har påvirket utslagene, alle de pillene han har tygget i seg… Men jeg tror den er noe som han har fått gitt inn den gangen gåtene ble delt ut, for å si det på det viset.

The question of authenticity or a true self is important because is it is accepted that it is an illness, completely separate from the individual, then there is little ambiguity about whether or not they should medicate or whether the individual is at any personal fault.

6. HEROES AND ANTI-HEROES: Negotiating stigma and diagnosis's double-sidedness

This section looks at how narratives of ADHD fit with the widely used hero/anti-hero trope, where heroes are exalted people with ADHD diagnoses, and anti-heroes are the images of deviants that overshadow ADHD.

Criminals and psychopaths

The link between ADHD in children and criminality and psychotic behaviour is seen as a risk. Research into ADHD and criminality has drawn deterministic conclusions from the correlations between prison inmates and the rate of ADHD diagnosis among them, which is reported to be as high as 50% in some studies (for example Molina and Pelham Jr. 2003). In abnormal psychology, there is also a push for early diagnosis of deviant children, or 'fledgling psychopaths' as they are also sometimes known (Lynam 1998). This also rated a mention during the 2009 Norwegian parliamentary election debates when a prison inmate with ADHD blamed some of his problems on his illness, and said it should have been noticed when he was still in school (Østlie 2009). Crime is a good arena for politicians to display their values (Christie 2006), and its easy to see how setting ADHD in the light of criminal risk draws attention to the need for preventative therapeutic intervention.

While a diagnosis can be a pragmatic tool for getting help, it draws with it some very negative associations. Anne erred toward self-censorship when comparing ADHD with psychoses:

> Anne: (.) Det er forferdelig å si det men (.) noen (.) Jeg vet ikke hvordan å si det uten at det skal bli misforstått. Men hvis du ser på trekkene på en psykopat og en ADHD'er, så er det faktisk en del felles. Og det er ganske ille (ler) syntes jeg.
> I: Det er…
> Anne: Men, ehh
> I: Psykopati er ekstremt alvorlig
> Anne: Ja! Men jeg syntes at vi har en del fellestrekk, altså hvis du går <u>konkret inn</u> og ser på hva symptomer er det med ADHD og hva symptomer er det med psykopati. Men altså, det er ikke dermed sagt at en ADHD'er er en psykopat.
> I: Nei det er <u>ikke</u> det du sier
> Anne: Nei det er ikke det jeg sier
> I: Nei det er det ikke.
> Anne: Men det er en del felles. Fellestrekk. Dessverre.

While emphasising that they were not the same thing, and that it is "a terrible thing to say" and unfortunate, Anne points out there are shared symptoms between ADHD and psychotic behaviour. Jan raised the same issue in the context of his stepson's biological father:

> Jan: …vi er av klar oppfatning at ADHD-en kommer fra hans far. …Faren hadde levd sitt liv utenfor hjemmet i stor grad, …og har klare psykopatiske trekk. Det vil si at, "*Hvor går*

> *grensen mellom ADHD og psykopati?*" Han har alltid vært et sjarmerende festmenneske når han er ute og ikke noe særlig når han er hjemme… Han banket sin kone… og var temmelig grov.

Their son has ADHD and his biological father is characterised as a violent psychopath. Elsewhere in the interview Jan emphasises how caring and kind their son is – so although he does have a past with drugs, he does not have his father's viciousness. Yet the possibility of a link between the two is not ruled out. Indeed, the Oxford English Dictionary's definition of psychopathy as "*a personality disorder characterized by persistent impulsive, irresponsible, antisocial, and often violent or aggressive behaviour, often accompanied by an inability to form normal relationships with others*" does bear a resemblance to many descriptions of ADHD.

It has also been mentioned in Stå På that lack of diagnosis among prison populations can lead to them being given the label, "treatment-resisting psychopaths." (Stå På, 2005, 4, 39) A mother in Stå På writes that these negative associations between the diagnosis to pathology and criminality "*make us, as parents, feel uncertain*" and are "*painful and scary for a 10-year-old… who is struggling to create a positive image of himself*" (Stå På 2006, 3, 27 and 28).

According to the interviewees, people with ADHD who took drugs did so because of an inner drive to look for excitement, and an unfortunate need to self-medicate. They avoided talking about risk-taking as a necessary or normal part of growing up. For parents with ADHD-children, this topic is a double-edged sword, as it both gives grounds for demanding extra care, but on strongly negative grounds. As Monica emphasised, "*It is so important we pick up these kids' ADHD early. I can't stress that enough*" and Anita who has extensive contact with prison inmates took the same line; but there is not consensus. What the interviewees reacted to was not the high rate of ADHD diagnoses among prison inmates, but the deterministic implications that this aspect of ADHD-discourse had for their particular children.

In appealing to others for understanding and kindness towards their children, parents risk their children being labelled as 'hyper' or likely to turn out to be criminally deviant. To be accepted, they have to put forward that they are like everybody else - normal and equal – but this can undermine their case for assistance. People with ADHD have to pass with stigma (Goffman 1963). Stigma is experienced in a variety of ways by people and families with ADHD: the schoolchild's stigma attached to being different in a normalising context; the stigma of having an inevitable genetic problem. Ways of managing this involve explaining

the diagnosis, defending the child with ADHD's good character, defending the family's standing and morality, and focussing on ADHD's positive characteristics.

A prominent method of countering negative representations that emerged from the interviews and is also used in Stå På, is to compare ADHD to other illnesses, particularly blindness and diabetes. The advantage of these particular comparisons is that people who are visually-impaired have well-known tools used for coping, such as glasses for mild impairments and stocks or guide dogs for blindness. Diabetes also affects people to degrees, and the breadth of its category has expanded to include those who do not have it but who are at risk of developing it (pre-diabetes). Promotion of 'diabetes awareness' and healthy diet is a popularly uncontroversial Public Health measure (Turner 2004). So too is ADHD a diagnosis where people can be classified on a scale,

> [ADHD] er jo som andre lidelser. Noen hard det svært hardt, noen har det bare litt. Som for eksempel med diabetes: Noen greier å kontrollere det med kostholdsregulering og lever fint med det…

and the implications of not treating the most pronounced forms are serious,

> … dessverre [er] det ikke en fremmed tanke om de verst rammede har en tendens til å begå kriminelle handlinger. (Stå På, 2005, 4, 38)

Likening the diagnosis to other illnesses that are understood to occur to different degrees makes it easier to present their children in a good light, both using the scariest risks as a basis for treatment, and emphasising the variety of ways the diagnosis plays out in each individual.

Normality/deviance discourse is a normative discourse, where those people defined as 'normal' belong and are accepted (Sirnes 1999). Sirnes (1999) and Solvang (2000) explain how this discourse is dichotomous, however in the case of ADHD it might be useful to conceptualise normality/deviance as each placed on opposing ends of a *scale*, as this is in keeping with how ADHD is seen as an illness and diagnosed. That is, all people can be placed on an ADHD scale, but will not be diagnosed until they have intense symptoms.

Interview subjects talked about the "extraness" of ADHD: the extra work in parenting, compensating for the extra difficulties their children faced, of having to constantly fight to make sure their children were getting helped at school, and in some cases their children's excessive energy. This discourse about 'extremity' in ADHD fits well with both the diagnostic criteria and stories in Stå På, because ADHD's diagnosis is not dependent on the *uniqueness* of its symptoms to its sufferers, but the *intensity and frequency of symptoms*. That is, it is not a question of whether a child is fidgety and inattentive, but how fidgety and inattentive, and how often. Likewise, the stories parents tell are just like other people's stories, only more so! It is this "extraness" that both creates the need for the diagnosis, and that utilised the right way can give ADHD'ers a competitive edge. ADHD is life in extremis:

the daily challenges are the same as for many others, but more pressing; the behavioural problems are the same as for many others, but more frequent and problematic. The behaviours and challenges faced by people with ADHD are presented as dramatic, intense and ongoing relative to other people. The symptoms of ADHD are made significant by their comparison to other people.

The April 2010 edition of Stå På has an article arguing that positive self-image and a positive image of ADHD is important; "*how you see yourself*" (Stå På 2010, 1, p.36) is a recurring theme. Similarly, the interviewees would like successful people who have these positive attributes to come forward as role models for others with ADHD, especially children. The problem with this is, people whose energy and impulsiveness is unproblematic and even beneficial, have no incentive to get an ADHD diagnosis, or to 'come out'. They may even object to being described in medical terms. For those who are successful, linking ADHD up to that success makes it less of an illness, and more and more like wellness. In which case, the bargaining power that was strengthened by the sick role is less sturdy.

The interviewees were active, and clear-minded about their goals, which consisted of helping their children be happy and make the most of their possibilities, and helping other parents. For both these goals, shared understandings and spreading information about ADD/ADHD is important: this is seen as the way they will raise an ADHD-consciousness, and break down stigma and stereotype. Supporters of the diagnosis use ideas that are more readily suited to criticising the diagnosis:

> Dysthe mener samfunnets trang til å sette en diagnose på alt som ikke passer inn under "normalen" kan være med på å forsterke problemene. "*Med en gang vi kaller det noe, er det plutselig noe galt med personen. Men hva er egentlig normalt? ADHD kan også være en ressurs og en drivkraft, og riktig behandling, enten det er med medisiner eller samtaleterapi, kan gjøre at personer med ADHD klarer å bruke disse ressursene. En diagnose er bare et verktøy for å få hjelp.*" (Stå På 2006, 3, 20)

Thus the small paradox that emerges, is that their children are both different and just like everybody else. Rather than break down the diagnostic order where their children are seen as having a shortcoming, they emphasise shared social responsibility, and an expansive embracing view of difference. They have a particularist approach to their cause, but they are part of a universalist pedagogic culture that emphasizes accessibility (particularly the education system reaching down to the lower class, and maximizing an equitable education setting, even at the cost of a few very high achievers).

Disadvantage and disability constitute their claim to extra entitlements. This is already familiar in the Norwegian setting: one can expect help, in the name of social justice. By acting in this way, they call into question the fairness of meritocracy. Simultaneously, the established school standard of meritocracy is still what their children will be measured up

against. They have to make the best of it, although perhaps conceding it has already beaten them. For example when asked what they thought of the school system, Anne answered, "*Jeg ikke synes noe om det i det hele tatt! …Det er bare til å lage taper av.*" Schools create losers, for this reason Anne devalues the school system and thereby rejects the legitimacy of being made a meritocratic loser. Anne is rejecting the process where her children are

> socialised into their disadvantageous situation even while they are learning and incorporating the standards against which they fall short. (Goffman 1963: 45-46)

Meritocracy is the traditionally "acceptable" way for schools to rank, and select or reject students. It has been called The Great Equaliser, because it is through academic achievement that the bright among the working class might better themselves, and even outshine their social betters. In practice, meritocratic achievement is still a phenomenon of social class inequality, the wealthy generally providing their children with more attention at home, better equipping them culturally, by already speaking the language of the educators. But since the opportunity to excel is still inarguably there for the talented, hardworking, focused student – despite class disadvantages – meritocracy's shortcomings are shrouded in favour of *a focus on individual responsibility and opportunity*: and those who fail have gotten their just deserts. ADHD-consciousness is a way of arguing against such meritocratic truisms. By pointing to a pre-determined outcome, the fairness of determining scholastic success by who 'fits the environment best' is brought into question.

Elaboration

The way family stories fed back into ideas about the diagnosis constitute a form of laymen's elaboration. Family histories, reinterpreted in the light of genetic facts, are used in a way that adorns and embellishes the scientific communiqués about the disease. Popular stories about personal experiences with the disease are like mirrors people recognise themselves in, and thus become guides.

Pernille Dysthe's (2006) autobiographical portrait of *Rita Linn*, a woman with ADHD, has been an important contribution in the Norwegian setting to understanding how ADHD is interpreted into the adult lifeworld (Stå På 2006, 3, 35). Articles attributed to her pseudonym *Rita Linn* have been included in Stå På, and the book is promoted in Stå På as well as available to order through the Association. Dysthe is a successful journalist and also a talented pianist, but these "seeming" successes hid the turmoil and frustrations (which in her case, were turned inward) caused by ADHD. Dysthe describes herself/Rita Linn as a passionate and driven woman, but one who has constantly suffered from anxiety, restlessness, misinterpretation of social cues and over-sensitiveness. All these characteristics are seen as

symptomatic of ADHD in women; and people recognise themselves when Dysthe describes her search for inner-peace. The interview material resounds strongly with her stories of restlessness and longing; and as a reader wrote in to Stå På about her experience of reading Dysthe's book, "*She wrote about me! Had she been watching me my whole life?*" (Stå På, 2009, 1, p.32). Dysthe's experiences, in turn, are recognisable cultural forms: passion, restlessness and longing have long since been canonised especially in poetry and music. Dysthe's and others' personal stories are examples of widening of diagnostic parameters to include success stories.

By insisting on the individuality of each person with ADHD, the Association is distancing ADHD from stereotypes about it, that is, distancing it from associations with its own symptoms. The association encourage the idea that ADHD is an illness that exists independently of its most notorious symptoms, such that successful and well people have it, too; even without knowing. Stå På contributes with a steady flow of information about ADHD as an illness with certain characteristics. At the same time, both the magazine and public spokespeople for *ADHD-Norge* encourage the understanding that not everyone with ADHD is the same. Stereotypes about what characterises people with ADHD are unhelpful because they blind people to understanding the individual with ADHD. This is summed up by the Association's motto: *Har du truffet et menneske med ADHD, så har du bare truffet ett menneske med ADHD.* The motto emphasises the individuality of those diagnosed, and has been used as the subtitle for an academic thesis, headlines in the mass media, and in Stå På. Behind it is the desire – the demand – for recognition. To been seen and valued as an individual, not to be treated as a "type" or a walking diagnosis: a rejection of medical definitions allows for recognition of the individual.

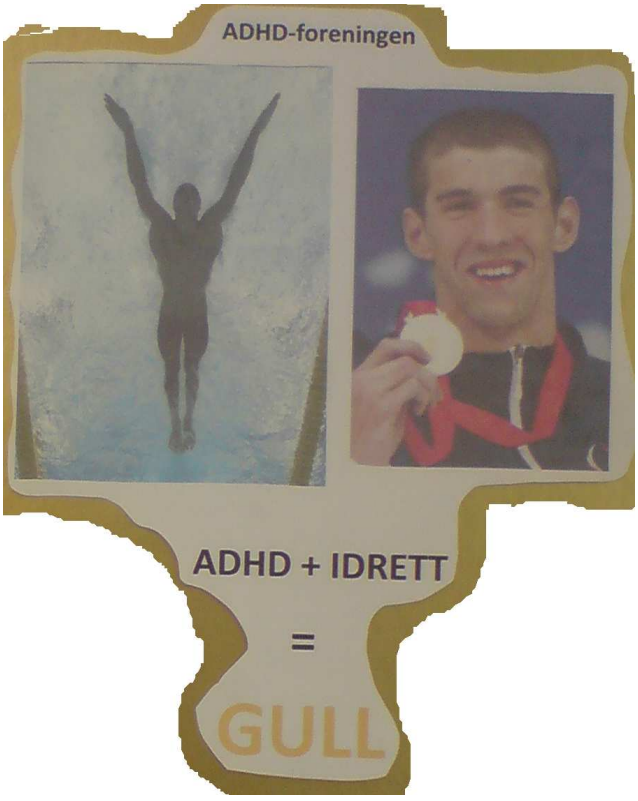
The stories mothers told echoed the psychological and educational messages coming through in Stå På. Governmental advice in the form of government documents comes through the newsletter. But the official documents from departments with differing focuses can contradict each other, as *ADHD-Norge*'s clearly annoyed General Secretary Tor Eikeland pointed out in Stå På (2009, 3, p.5). The Health department claims that ADHD is an illness, while the Education department claims that ADHD is best seen as controversial. Following this, leaders from *ADHD-Norge* met with relevant government representatives (ADHD-Norge 2009), demanding clarification. Since then, Health minister Anne-Grete Strøm-Erichsen has stated:

> Noen hevder at atferdsproblemene er av utvikingspsykologisk karakter og skal behandles med atferdsterapeutiske tiltak. Andre hevder at atferdsproblemene har en nevrobiologisk årsak sammen med

utviklingspsykologiske eller andre tilleggsproblemer, og at de skal behandles med legemidler i tillegg til psykososiale tiltak (Stortinget 2010).

Co-opting criticisms: ADHD + sport = GOLD

A Google-search on "ADHD Norge" revealed an article suggesting the ideal way to solve the 'problem of ADHD' would be if people with it refrained from breeding at all, but concluded that since ADHD is so widespread, it would not be practical to stop them (Blydt 2005). Eugenicist views on ADHD are made possible when the genetic component is emphasised. There is academic literature on the high prevalence of ADHD among the American prison population, arguments that early intervention reduces risk of becoming a drug addict, and suggestions that people with ADHD are not suitable for the military and should not drive cars because of their supposed increased risk of distractedness and accidents. Counter to these negative genetic discourses about ADHD, the Association website reports the findings of a Swedish study indicating that people with ADHD have a lower risk of accidents in traffic (ADHD-Norge 2009). A driver's license is a important symbol of adulthood and masculinity, in addition to being an employment enabler (Myklebust and Båtevik 2009).



Further, ADHD is argued to be "an advantage", by focussing on the strengths of ADHD such as stamina and energy, for all they are worth. This is associated with an us/them discourse that celebrates difference (Solvang 2000). The more a group is excluded by the stigma, the stronger the group's sense of belonging and sense of 'us' becomes. Emphasis on the uniqueness of the individual and the variety of ways the illness plays out allows us to understand ADHD both as an illness, and under the right conditions, an advantage:

Hege: ADHD'er har utholdenhet uten like!

Anita: Som vi sier, ADHD pluss idrett er lik gull!

Nina: The great thing about hyperactivity is that a lot of Hyperactives have such great stamina! My son has told me he is glad to be hyperactive, because he can do so much more than other people do.

They assert that people with ADHD have incomparable stamina, and can be gifted athletes. ADHD-diagnosed swimmer Michael Phelps, who holds fourteen Olympic gold medals, is chosen to represent his stigmatised category (Goffman 1963).

The association co-opts the criticisms of the diagnosis held by the sceptics. The reasons suggested why the diagnosis should not be necessary are used instead to change the diagnosis's image. When critics of the diagnosis point to the energy many children have as a wonderful thing, proponents of the diagnosis agree that the energy can be great[4]. Anita's interpretation is that ADHD is found in people with phenomenal ability, energy and stamina – like Michael Phelps, and like her father. Anita described her father as a successful and daring fisherman whose ADHD gave him the competitive edge over other more careful, cowardly fishers. Anita's perspective is that ADHD-people are indeed the heroic 'demigods' and 'wildest colts', but also that ADHD is a real biological condition requiring special attention and treatment. This *pride* is developed in cooperation with, in conversation, with others. The support groups and peer telephone numbers are not only a helping hand and someone to listen during a crisis, but also part of a group process of developing pride in the positive aspects of character traits typical of people diagnosed with ADHD.

[4] The children's adventure story series Percy Jackson concerns a boy who is a demigod or 'half-blood'. His father is a Greek god. Percy is a problem in school and diagnosed with ADHD and dyslexia. Here is an extract from the encounter where Percy is told about his true identity:

> *"Diagnosed with dyslexia. Probably ADHD, too."*
> *I tried to swallow my embarrassment. "What does that have to do with anything?"*
> *"Taken together, its almost a sure sign. The letters float off the page when you read, right? That's because your mind is hardwired for ancient Greek. And the ADHD – you're impulsive, can't sit still in the classroom. That's your battlefield reflexes. In a real fight, they'd keep you alive. As for the attention problems, that's because you see too much, Percy, not too little. Your senses are better than a regular mortal's. Of course the teachers want you medicated. Most of them are monsters. They don't want you seeing them for what they are."* Riordan, R. (2006). Percy Jackson and the Olympians: The Lightening Thief. New York, Hyperion.

The traits that led to his ADHD-diagnosis make Percy better suited to his warrior tasks. That, and the double entendre about teachers being 'monsters', constitute a light-hearted suggestion that the diagnosis is a convenient way of labelling inconvenient problems.

Similarly, 'Wildest Colts', a popular American book on parenting, uses the fieriness of horses as an allegory for children and the adults they become. The wildest colts are the most difficult to handle, but they need the best handlers, and have the most potential for performance. The author's advice to parents is that they refocus on taking delight in their children.

7. RESISTING FATE WITH KNOWLEDGE

This chapter looks at how everyday difficulties, and worries about the problems envisaged to lie in the future are handled by a 'thinking positive' story of resistance and struggle. Fate, unfairness and lack of understanding are seen as being overcome by factual information and increased knowledge. The heroic image of ADHD is furthered by the challenge of fighting the ignorance in the system, and fighting fate itself.

Mastery, coping and possibilities

Mastery and coping are concepts used in areas as diverse as special education, to unions. It means a positive focus on what can be done, not a negative focus on weaknesses. Norway's democratic socialist "work-fare" (Hanssen, Sandvin et al. 1996) system (which emphasises the social contract between state and individual through work, taxation and welfare) has a particular focus on inclusion: mastery is a key concept within initiatives ultimately aimed at that.

Mastery and coping (both *mestring* in Norwegian) were also employed by ADHD parents I interviewed. However, there was also wariness towards "mastery" and in some cases a distinct re-articulation. Mastery represents competence and achievement, but it is easier said than done. Mastery is desirable, but it also means that before mastery is achieved one is a failure, or worse, a total failure if one never achieves it. Rather, ADHD parents talked about "possibilities", a concept not bound by the qualitative success/failure dualism, rather it embraces by definition all things possible, without rank. "Possibility", as a concept, also illuminates constraint, as well as calling in dreams, hopes and creative ideas.

Special education is a resource considered suitable for some people with ADHD and special educators received a lot of praise from parents throughout the interviews. Special educators work with children who are having a difficult time both in social terms and learning terms, under a series of modern social and educational constraints. An interesting exception to the class-room constraint was provided by children serving lunch. From my interviews I can say with certainty that some parents would strongly support this type of initiative, and others would be opposed to their child being removed from their learning in a normal environment.

As mentioned earlier, the identification of ADHD as a disease can be interpreted as a result of modern school environments and the demands of modernity. But sometimes exceptions are created in the modern system, giving students an opportunity to do something

both physically active and useful; as for instance in the case of students who were having particular trouble in class being given "time out" to make lunches. This allowed them to be of practical help and to avoid the setting that was making them into a problem (Andersen 2009).

The interviewees knew their children have the right to adapted education and ILPs, but what they mean in practice or how to make a school find out what practices work for their particular child is less clear: but every interviewee mentioned that having the good luck of meeting a flexible teacher (or understanding employer) was important. Monica spoke warmly about one of her son's teachers:

> Han var lærer i realfag. Og han lærte altså gutten min ting som han hadde gode evner til, fordi det var faren veldig flink i også. Grunnet læreren… fikk [han] lære så mye. Så vi fikk til et veldig godt samarbeid. …[Han] kommer hjem nå med 6 i matematikk og gjør det bra på skolen. …alle ser opp til han som er så flink og kan så mye om programmering og slikt… Han er en veldig vellykket gutt og har det bra i dag.

I: Ja men så bra!

Monica: Og trives og har kompiser og kamerater.

Her son had been lucky and gotten a great teacher who nurtured her son's talents in mathematics and programming. He soon started to get excellent grades in those subjects, and Monica later explained how this led her son to become more confident and to make friends at school. It is also this success in playing his strong hand that helps the family tolerate his behavioural problems.

Anne was in a different situation when she decided to seek help with her children. Anne talked about the process of getting help for her child, an adoptee:

I: Var det slik at du og mannen din tok ham til legen og sa, "*Vi tror han har ADHD*", eller?

Anne: Nei. Det var jo ikke sånn fordi vi visste veldig lite om ADHD den gangen. Helsestasjonen visste ingenting, barnevernstjenesten visste ingenting og liksom alle som skulle være våre støttepersoner visste ingenting. Sånn at, vi måtte jo gå ganske hardt ut på Barnevernstjenesten før de gikk med på en utredning. Jeg hadde jobbet mot Barnevernstjenesten i, i hvert fall i 3 år, for å få en utredning. …Når han da kom til utredningen så var det ingen problem, altså. Da fikk han diagnosen. Ganske kjapt.

I: Så dere hadde det vanskelig med han i omkring 3 år, og så når først dere kom til den rette personen så fikk dere den diagnosen.

Anne: Ja

I: Ja, OK. Du sa før at du måtte presse folk som skulle hjelpe deg for å få utredet barnet. Var du misfornøyd med dem eller tror du de ikke skjønte helt?

Anne: Jeg tror ikke de skjønte, fordi de hadde ikke kunnskap… [Men] nå har vi havnet ganske greit ut, men det handler igjen om legen vi har fått, tenker jeg.

I: Er det en spesialist her i byen?

Anne: Nei, dette her er en som jobbet på [et sted] i mange år. …Sånn at dette er en som har sett en del ting og opplevd en del ting på kroppen selv. …Han er ikke så redd for å prøve ut ulike sammensetninger.

All the people who were supposed to help seemed to know nothing. After three years of trying to get a diagnosis, when her son was finally in the right place, he was diagnosed swiftly. In the mean time, Anne had had ongoing experiences of feeling like she was not heard or understood by people in institutions from whom she was entitled to receive help. Eventually, they found a doctor who had 'been around', and was willing to try different

dosages. Immediately after referring to this doctor's willingness to 'try out' different drug combinations, Anne was careful to point out that it was not only the medications along that helped her son, crediting her son with increasing maturity:

> Men han har jo modnes også, på det siste året da. Han har blitt mer voksen. Jeg ser at han er på vei til å bli voksen; og jeg tror det hjelper på også.

His increasing maturity helps him; it is not only the good doctor they came into contact with. With deliberate naivety, I asked if Anne then also meant he would grow out of having ADHD. In response, she put her coffee mug down hard on the table. She explained that if since she was an adult with ADHD, then it must be obvious that people do not grow out of having it. The difference that maturity adds is that people become increasingly able to manage their illness, through the use of strategies:

> Jeg ser i ettertid at jeg brukte strategier for å komme meg gjennom høyskolen. Jeg har klart meg, og sittet flere år under utdanning. Det er ikke noe i veien med hodet i den forstand, men å finne de ulike måtene å kunne (.) mestre det på. Det er jo det det egentlig handler om. …
> Skole er en ganske stor del av livet vårt, [men] jeg kan ikke lese en bok. Jeg klarer ikke å konsentrere meg. Jeg kan lese den samme siden hundre ganger og forstår fortsatt ikke hva som står der. …Men hvis jeg går på en forelesning, og jeg klarer å knytte til meg folk som liker å diskutere det som foregår på forelesningen, og vi kan sitte sammen i grupper, så får jeg det inn. Heldigvis så fant jeg mine som likte å lære på samme måte som meg, og derfor klarte jeg meg ganske greit. Jeg vet ikke om du forstår utrykket "knagger å henge ting på"? …Det betyr at du må finne din måte. … For andre er [min måte å huske ting] veldig innviklet. Men det er bare at sånn må jeg ha det…

Anne learned to manage her ADHD through strategies. She claims not to learn well through the written word, but while taking further education she learnt through discussion with others who had been to the same lecture; and uses a conscious visual process to remember her telephone number. In other words, even though she got the diagnosis at an adult age, Anne sees in hindsight that she did have ADHD. Recalling her own difficulties helps her relate to her children's:

> Anne: …Og sånn er det vel for ungene også, sant? Altså, prøver å sende videre til de at, "*Hvis du kan, går det bedre for deg hvis du kan? Å gjøre det sånn og sånn*." Eller, "*Er det et bilde du kan se foran deg som kan hjelp deg til å huske ting?*" Du må lage disse måtene, og det er det vi kaller for "knagger". …Det er liksom strategier som er lette å huske, som gjør at jeg klarer å huske akkurat <u>det</u>.

Anne emphasises that people have their own special techniques they develop for doing things. She uses her consciousness about ADHD and the environmental requirements needed for people with ADHD to succeed, in solidarity with her children. By being open about her own ADHD and also being a reasonably successful person herself, Anne is contributing to a more positive image for the diagnosis.

Hilde told the story about her son's ADHD in the light of the experiences she and her father, Petter, had had at school. Petter had not fitted in well to the classroom learning environment:

> Hilde: Det vi kan konstatere 99% sikkert uten at de noen ganger utredet det er at min far også hadde ADHD. …Men han fulgte aldri vanlig undervisning, og han hadde metallsløyd i hele ungdomsskolen og han ble

> bare hentet når de skulle ha prøver. …min far var nok i den kategorien som hadde fått diagnosen men heldigvis la skolen han, han reparerte alle bilene til lærerne på ungdomsskolen. Han hadde nøkkelen til rektoren sin bil å kjøre til verkstedet i skoletiden og det var sosialt akseptert.

Hilde is certain her father would have been in 'that category' that gets diagnosed with ADHD, but "luckily" the school principal found a way to interest and engage Petter instead, by giving him the keys to his car, and letting him drive it to a garage to work on it. In other words, Hilde's father only did the things he liked which were metal-work and mechanics, "*for all of school… [except] when they had tests… and that was socially acceptable*". Hilde had similar difficulties with some classroom learning as her father, but unlike him she was not given any freedom at school. Rather,

Hilde: Når jeg var 13 år var PPT kommet opp mot meg men jeg fikk beskjed om at jeg var lat og ikke giddet. Sa jeg kunne hvis jeg ville (sukk). Så tok de meg ut av alle de timene som jeg likte, for at de skulle være norsk og engelsk. Så de fagene som jeg likte tok de meg ut av for å få disse og disse.
I: (ler) Det der er det verste jeg har…
Hilde: Og jeg fikk, mor fikk beskjed om at jeg hadde vært mye bedre hvis jeg bare giddet. "*Men hun er lat*."
I: Oi

Hilde was taken out of classes she liked by PPT so she could catch up on her weakest subjects, Norwegian and English. After saying, "*PPT [told me]… I was lazy… I could [do the schoolwork] if I wanted to*", Hilde sighs, indicating the incorrectness of PPT's position, so that the interviewer then understands that Hilde was *not* lazy or negligent and *was unable* to do the schoolwork even if she tried. Then Hilde repeats that she was withdrawn from classes she liked, creating cumulative emphasis on scandalous damaging aspect, which elicits suitable appal from the interviewer, "*That's the worst thing I've ever…*" Further, her mother was told that Hilde was lazy: the interviewer then presumes that PPT caused Hilde's mother unnecessary grief (for something her daughter was innocent of) or a mother-daughter conflict. The contrast between the stories Hilde tells of her father's and her own experiences in school serves to dramatise the disciplining power of the PPT, and bring out the helpless vulnerability of the position Hilde was in at that time. In this re-telling, she was a victim. Her father had luckily not needed a diagnosis; she had unluckily missed out on any socially acceptable outlet from normal school or a liberating diagnosis. After this, Hilde told the interviewer how she worries how her son will be handled: whether he will ever experience the idyllic acceptance her father Petter was met with; or the unjust humiliation and disciplining she underwent.

Hilde's strong dissatisfaction with special education was shared by Anita, Anna, Hege, Nina. Anita held that:

> …Hadde spesialundervisningen fungert så ville jo grunnlaget for det som går på videregående fungert bedre, sant? Det er her, på barne- og ungdomsskolen de største vanskene sitter. Det fungerer ikke. Hvis spesialundervisningen hadde fungert så ville det vært lettere på videregående. De drar problemene med seg. Og så sender de hele problemet til NAV.

Medical authority is of limited usefulness to the ADHD cause. The medical is only used as much as is needed to give their difference an authoritative and legitimated standing. After that, ADHD is seen as belonging to the psychological and pedagogical experts' paradigm. Lifeworld narratives reveal biological interpretations of ADHD to be practical and symbolic empowerment.

In Stå På, ADHD was frequently described as a disability or learning disability. This is an interesting assertion, because it has been argued that diagnoses are sought, and inappropriately given, in order to get more funding for schools for more children "with problems". While asserting their children's needs, parents are also careful not to present them as being without potential or overly weak. For the parents interviewed though, they knew they did not have children with life-threatening illness; but they do think their children need special consideration, and many worried about how work and living arrangements would be for their children in future. [5]

There are three discourses at work: normality/deviance, equality/inequality, and us/them (Solvang 2000: 5). People with ADHD require adapted education and flexible work arrangements, but despite seeking 'special treatment', they are 'normal' and just as different from each other as with others. They are just like everybody else. Needing each of these aspects to be understood (normal and do not want to be stigmatised / special adaptations needed / proud of their individuality and uniqueness), they take a trifocal view.

Interview 1

Anne: Spesielt vi foreldre, vi legger til rette for de hele tiden, vi går inn på møter på skolen, "Ja, de må ha det sånn og sånn", søker om hjelpemidler, altså, vi er jo hele tiden på plass og styrer dette, sant? Og demper og demper og demper. Men den dagen du på en måte ikke er der på samme måten så vil jo utfordringene til disse ungene komme. Det er da de møter verden. Jeg ser for meg at det vil være tøft å slippe taket fra hjemmet når de skal ut og søke på sine egne veier. Da er ikke mor der lenger for å ordne på samme måten.

I: Det høres ut som om du ikke har helt tro på at de kommer til å være helt selvstendige.

Anne: Jo, på sikt så tror jeg at de vil det, men altså, på veien til å være der så trenger de støtte og hjelp.

[5] The child's best interests: An often called upon representation in popular mass media in discussions on ADHD is "what is in the child's best interests". The child-centred parenting approach (as for instance outlined by child-psychology guru Penelope Leach) is also critical of ADHD as a diagnosis and its treatments. According to Leach, ADHD can in some case be solved by a change in teachers or schools, and she states, "Children should be taught, not drugged." Coming from one of the Western world's most authoritative voices on modern parenting, this stance can easily be interpreted as meaning that giving children Ritalin (et cetera) for ADHD reflects a lack of 'appropriate' teaching, or some other environmental problem. The implication that the parents could or should be arranging something differently in their child's life aligns with both the radical anti-psychiatry position and the ADHD-sceptics' position. While the radical anti-psychiatry position and ADHD-sceptics' positions are relatively straightforward to rebut (using authoritative medical sources as evidence, or by appealing to commonsense notions of individual autonomy in action), ideas about "what is best for the child" are neither easy nor desirable to distance oneself from. The question becomes not whether to use this discourse, but how to take an ADHD-positive stance within it.

Interview 2

Monica: [Datteren min] sliter mye mer [enn sin yngre bror] fordi hun tåler ikke Concerta ((methylphenidate)); og hun har veldig mye angst og depresjoner… Men hun er intelligent, hun også; sånn at hun har greide å ta [utdanning] og fungerer da i en 80-prosent stilling. Men nå vil hun søke om Ung- og Ufør fordi hun har veldig lyst å ta [videre utdanning]. Men jeg vet ikke hva hun vil velge. Fordi du vet at hun har mye mer med dette med økonomi og rastløshet. Flytter mye, greier ikke ta vare på ting.

Interview 3

Hege: Vi ønsker at de skal komme ut og bo alene. Hvordan, hvilken hjelp får de, da? Det er ikke sånn med boliger, at de er lagt opp til at de kan ta imot disse barn når de først er i den store verden. Det er mer de som er psykisk utviklingshemmede som er, eller de fysisk funksjonshemmede, de som sliter med autisme eller de med Downs Syndrom (.) De. *De* har behov for andre hjelpetiltak enn disse med ADHD. …
Det er der på en måte at vi kommer ut i en felle hvor de har ikke tatt vare på de som de ikke vet hvordan de skal ta vares på. Så da. Da blir det vanskelig. Og hva skjer da? Hvis vi ikke er der og hvis ikke noen andre er der, da blir de overlatt til seg selv. Jeg hørte jo selv en mamma som – hennes jente hadde blitt 17 år, og nå må hun begynne å ta litt ansvar selv for sitt eget liv, hun må huske selv å ta medisin og sørge selv for å komme på skolen, og det ender jo med at hun ikke *tar* medisiner og hun *kommer* seg ikke på skolen. Så, vi blir jo slitne og lei, og vi har lyst å ha våre egne liv, også! Men, jeg føler at de har bruk for oss i mange mange mange mange år. Altså, vi må være der, inntil det systemet kan på en måte ta vare på de, sant?
… Min sønn sa i helgen at han skal ha et stort hus med 2 kjellerleiligheter, for da kunne jo mamma drive å passe på og styre nesten alt (ler).

I: Å?

Hege: (ler) Og det var eldste gutten! Han er ikke interessert i (.) Han har begynt å ha meninger om hvordan det skal være når han blir voksen. … Men jeg er veldig spent på hans utvikling. Man skal aldri si aldri. Men, det er klart jeg har bekymringer i forhold til de ungene og, ja, jobb. Hvor skal de ende med å jobbe? De har jo vernete bedrifter, men de er for de som er mye svakere igjen, sant?

Nina acknowledged she will need to be an active parent for a long time, and mentioned that more children were out of the question because her son requires a lot of her attention and help.

On one hand, people with ADHD are *not* suffering from a problem so serious that it is obvious to anybody and severely limiting. On the other hand, parents of children with ADHD are concerned about whether their children will be able to finish their education at all, get any kind of job, and manage relationships. So then, to what extent does this diagnosis provide any help when it comes to getting resources? That is a sore point.

The pending update on guidelines for handling ADHD will reiterate the role of ILPs in assuring students get the help they need through school. However, both Solvang and Isaksson et al (2007; In press) point to an inherent difficulty with this. ILPs are disabling in that they identify the student's impairment as the problem, not the educational environment (Isaksson, Lindqvist et al. 2007).

Fighting ignorance

Anita has an adult daughter who used drugs heavily for several years, and drew on support from health services and her parents in order to stop using. She finally got diagnosed with

ADHD in her mid-20s, during her drug recovery. Shortly afterwards she went through a series of seven job placements. A few placements worked for a month or two, but all failed eventually; she was also offered courses. The social welfare services ran out of ideas, and consequently Anita's daughter was offered a full disability pension before she had even reached the age of 30. Rather than agreeing her daughter resign herself to this, Anita helped her to find a workplace that would let her work in a 40% position with the hours spread out over a few days, and with a sufficiently varied work environment. The problem for Anita's daughter and many others with ADHD is that they get "burnt out":

Anita: Det er mange som sliter med [ADHD], som brenner sitt lys i begge ender. Full fyr her og full fyr bak. Det går på hele tiden. Jeg snakket med en dame, hun er utdannet pedagog og fikk ADHD diagnostisert i fjor. *"Hva problemer har du?*" sa jeg. *"Har du noen som kan komme hjem å rydde hos meg? Det er fullstendig kaos.*" Men det er mer enn bare det. Hun sliter. Hun fortalte meg at hun har aldri hatt en jobb lengre enn 8 eller 9 måneder. Enten skiftet jobb eller blitt sykemeldt.

I: Hun ble utmattet?

Anita: Ja, utmattet. Gått på fullt. Så jeg visste at for datteren min å bli 100% [ufør] og sitte hjemme i leiligheten ville aldri ha fungert. Når datteren min ville jobbe 40 prosent, da så jeg hvor *viktig* det er *at de 40 prosentene blir fordelt*. For hun kan også brenne sitt lys i begge ender. Det er veldig viktig at det blir passet på. For de blir fort oppbrukt. De har lite sosialt nettverk, mye ensomhet – så jeg gjorde det jeg kunne for at det ikke skulle skje. Nå så jeg i medlemsbladet som kom i går at de skal ha en stor konferanse i Oslo, og den konferansen gikk ut på at det er så mange som har ADHD som er uføretrygdet. At man heller skulle se på muligheter. Så der er jo min datter en prototype på hvordan det kan gå.

Anita sees her daughter as an example of how well-adapted work conditions can work for adults with ADHD. It this case, it was dependent on finding a workplace flexible enough to allow her to work a little, without getting burnt out - or relapsing. It worked so well that eventually the employer expected her to increase to a fulltime workload. When it came to facing the employer to explain why she would not be able to increase her workload, Anita was enlisted to go with her daughter. With the help of Anita's solidarity and mothering, her daughter has become an example of things turning out well, despite some bumps along the way.

Anita has played an important role in getting her adult daughter off drugs and into work, but this was sometimes hindered by the regulations for confidentiality and individual privacy:

NAV kan ikke dette med tilrettelegging for unge voksne med ADHD. …Når de er så voksne så er det taushetsplikt, foreldrene kan ikke påvirke noe, sant? *"30 år er du."* Der sitter [voksne med ADHD].

I: De må gjøre det selv?

Anita: Ja. Men hjelpeapparatet trenger faktisk viten, trenger opplysning om hvordan de fungerer i hverdagen. Så taushetsplikten er et hinder. De skal selvfølgelig ta ansvar for eget liv, men så er de ikke alltid i stand til det, og trenger noen som kan hjelpe.

The expectation from the social services is that people of legally adult age are supposed to look after themselves and be independent of their parents – unless they are fit to be institutionalised. Anita (and other informants) feel strongly that many people with ADHD fall between these categories, and become a problem for the social services because schools and

the social services do not know how to adapt environments to their needs. Further, Anita thinks that despite NAV's legal duty to provide information, the people at NAV know too little about what possibilities are available that suit people with ADHD:

> Jeg har aldri opplevd vrang vilje fra hjelpeapparatet (.) Men det kan oppfattes sånn. De mangler viten. NAV har jo opplysningsplikt. Men den holder de ikke. Hvis du ringer til NAV for at de skal si til deg hvilke muligheter du har, hvilke muligheter som finnes. Sant de må snakke om mulighetene og hjelpe folk til å finne fram til de. Jeg synes en må vinkle det positivt.

After saying she has never experienced ill will from the social services, Anita pauses: "*But it can be perceived that way.*" Anita is positioning herself as cooperative, reconciliatory, even omniscient. Problems encountered by people seeking assistance for their ADHD are because of ignorance among those employed in social services: "*They lack knowledge.*" Anita's views echo the findings of the Auditor General's report, where the Deaf Organisation are cited as arguing the main problem is ignorance about the available adaptations [6].

Anita is both knowledgeable and *thinking positively* (as opposed to those who are ignorant and/or critical). Nonetheless, NAV is still portrayed as being in the wrong, as they fail to provide information and do so in a *positive* way: "*One has to put a positive angle on it.*"

> Begrensingene, de vet vi. Men det er mulighetene de ikke vet om. Du kan si at, her finnes det mange muligheter for ungdommer med ADHD. For eksempel, en kombinasjon mellom skole og arbeid, praksisplasser, lunsjtilskudd, og skjermet bedrift. Og ARK ((Arbeidsrådgivningskontoret))! … Selv de som sitter på NAV, vanlige saksbehandlere vet ikke om ARK. Så når [voksne med ADHD] har vært på X antall tilrettelagte yrkesfør attføring, og de ikke fungerer, så skal de enkelte NAV kontorene sende de til ARK. Saksbehandlere forstår ikke, etter at de har prøvd flere ting, og de tingene ikke funger. Så settes de på yrkesføre attføring som ikke fungerer. Så går de bare tilbake til rehabiliteringspenger. Og så hva gjør vi her? Kommer ingen vei. *Da* skal NAVkontorene sende dem til ARK. På grunn av ARK her i byen, det er utprøving av psykologer, testing av evner. De skal teste *muligheter*, sant? Da kan de finne ut om du passer til å jobbe med barn, fabrikk, passer du til salg, passer du til butikk, passer du til sykehus, hva for begrensinger eller muligheter har du. Så det hadde vært fint om ei slik oppgave du har kunne fokusere på mulighetene, og så mangler systemet rett og slett informasjon. Det er det de mangler.

Anita demonstrates her extensive knowledge of the NAV system and claims that, "*There are even ordinary case-handlers working at NAV who don't know about ARK.*" She thinks that after work placements fail for people with ADHD, case-handlers are confounded. Further, case-handlers do not realise that they should refer people with ADHD who are NAV clients to the ARK section at NAV. Anita argues that if they did this, the psychologists working at NAV would be able to do their job, and the people with ADHD would not revert to the rehabilitation pension: in her view, information and knowledge are the solution. Anita interprets difficulties people with ADHD have with the social service system in terms of the

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[6] "*Organisasjonen mener at hovedårsaken til manglende tilrettelegging for hørselshemmede er uvitenhet og manglende bevissthet om hvilke hjelpemidler og virkemidler som finnes*" (page 49).
Barne- og likestillingsdept (2008-2009) "Riksrevisjonens undersøkelse av adgang til samfunnslivet for personer med funksjonsnedsettelse." Dokument nr. 3:10 (2008-2009) Oslo, Riksrevisjonen.
<http://www.riksrevisjonen.no/Revisjonsresultater/Dokumentbase_dok_3_10_2008_2009.htm> Accessed 13th July, 2009.

lack of understanding and knowledge about what adaptations work well for people with ADHD; rather than personal shortcomings among people with ADHD. By taking a positive focus on what possibilities people with ADHD have, the burden of responsibility for the problem is shifted off the individual and onto the system. Further, not taking a positive focus is associated in Anita's portrayal with culpability and 'what can seem like ill will'.

8. Discussion

Social movement's identity and lack of doubt

The ADHD movement illuminates the power connected to education as an institution, and the shortcomings of both the biologically-oriented and the social normalisation-oriented tradition in education. Interviewees told me they were doing what is right for their children: they are caring for them by getting them medical attention and alternative schooling options. They seek to be heard *within* the system.

The things left unsaid in the interviews became interesting. While ADHD can be considered controversial, there was no hint of the parents doubting either that their child's behaviour should be characterized as illness, or that the diagnosis was appropriately applied. They did not directly bring up the topic of ADHD's controversies, but showed polite irritation (or sadness) when I did. In their final analysis, understanding and accepting ADHD is a question of knowing about it and *having knowledge*. To some extent this reflects the methodology: interviewees were found via the ADHD Association, and they had approached the association in the first place, willing to join it. Already being connected to the group and having to some extent an ADHD agenda and positive attitude. Those attached to the Association are already in an identity forming process where self understanding is connected to the diagnosis, and this effect is even stronger when the diagnosis is perceived as running in the family: this is the group 'we'. This we stands in contrast to the 'other': those who are unwitting and unknowledgeable about ADHD.

Interviewees demonstrated their awareness of the problematisation of ADHD through expressions of sadness and irritation. When I asked about controversies and repeated what scandalous news I had heard about ADHD in the mass media, the interviewees were insulted. Controversies about the diagnosis or its amphetamine treatment were not seriously acknowledged, except in the case of the step-father of an adult with ADHD who was recovering from a drug abuse past. Rather, they focussed on establishing their standpoint, which is that ADHD is real, misunderstood, and has positive sides to it. This way, they worked further developing people's understanding of their group as a *valuable* group.

While the association through Stå På sends the message that people with ADHD are not all alike, the interviewees told me the details about their child's (or their own) diagnosis and relationship to their personality. The interviewees were specific about whether it was ADHD, hyperkinesis, or ADD; and whether there was "co-morbidity" (as it is depressingly

called in the psychiatric literature) with other diagnoses. All the interviewees knew technical information about what medication they used or had tried, at what doses. They told me about what their child said about themselves and their diagnosis. They told me how they had coped with their own ADHD, and what degree of ADHD they have. Being specific is a way of individualising ADHD, stopping the individual being obliterated by the generic illness label. Despite seeking and supporting the diagnostic label, parents refuse to define their children totally in terms of the diagnostic frame.

But while they spoke about their individuality, and how they understand themselves/children/family through the diagnosis, their certainty about what ADHD is was note-worthy. The Association has already created a "we" or an "us" – and that means there is already an "other". In this case, the others are the ADHD sceptics, and they are that way because they are not enlightened about ADHD's true nature: they simply do not know enough about it.

The informants were aware of the 'dark side' of getting a medical diagnosis, in what it implied for their children. It comes at a price, but it is seen as necessary in order to have help made available for their children.

While an important analytical tool, Conrad and Schneider's (1992) theory of medicalisation did not have the scope to illuminate 'suffering' as a driving force behind the medicalisation of deviance. Solvang's (2007) reconstruction of Conrad and Schneider's (1992) "light and dark sides" of medicalisation was better able to capture the humane aspects of medicalisation, while remaining sensitive to the reductionist manner biological explanations of deviance operate in, and the new negotiations of stigma and morality that occur in the wake of diagnosis.

Parents do have to negotiate conflicting discourses when discussing their treatment decisions and their children's diagnosis. They show (1) why it was necessary to get the diagnosis, and how difficult it was to achieve and how long it took. They had to insist something was wrong, and this was where they used their authority as parents who knew the child best. But (2) although *fighting* for their child's best, they present themselves as suitably *passive* in the medical encounter, as accepting expert advice. The parents become lay-men on ADHD issues and definitions, and draw their knowledge from group discussions, Stå På, formal documents and scientific literature.

Re-interpretations of family histories also change after receiving the diagnosis, and there are sometimes concerns of genetic inheritance being a burden that can laden the next generation. Guidance for where to look in the family tree for the carrier of the responsible

genes is provided by stories in the association magazine from people in the same situation, and from medical experts. The ways that genetically-based factors play out are understood as being highly contingent, and this is a motivating factor in their political campaign.

Heritability is social, and the ways it is subjectively interpreted are contingent on both social roles and the guidance of expert knowledges. In genetic conditions, a reinterpretation of the family's history can come in to play, and the family history in turn feeds back into how the condition is interpreted. The genetic aspects of ADHD help create a strong loyalty to the diagnosis, both as a form of solidarity with individual children who have the diagnosis, and because the diagnosis has come, in part, to capture an image of the family's heritage.

While accelerating the medicalisation process in some ways, they also retard the growth of its domain as they negotiate the stigma dilemma that the diagnosis draws with it. The group use the worst-case-scenario biologically-determined outcomes to support their demands for educational and welfare resources to help them address ADHD's difficulties. In doing so, they are insisting on the interwoven nature of biological facts with social and psychological factors. The interplay of biological, social and psychological factors (which to the sceptics', can be construed as contradictory) is part of the 'obvious', taken-for-granted knowledge for people experiencing ADHD as part of everyday life.

The association is attempting to create a new image for ADHD, and this is done especially with self-esteem as a driver. The association's message through Stå På that, "*ADHD would be less stigmatised if people were less insistent these days on getting a diagnosis and always trying to be perfect*" is a sociological contradiction. However, from the lifeworld of sufferers, it makes sense. The assertion is built up from a foundation of understanding that the diagnosis can change the nature of the whole family tree (including the parents' self-image), and that without the diagnosis the child's best is not being served. Positive portrayals of hyperactive, impulsive, and distracted characteristics, which are normally associated with "boys will be boys" and scepticism towards the diagnosis, are co-opted. This is enabled by the elaboration of the diagnosis to include more than the most obvious examples. Treasured examples of famously successful people, who are open about their ADHD diagnosis, are used to counter deterministic stories about ADHD's relationship with criminality and psychopathy. Although making use of the diagnosis, people strongly resist being characterised *solely* in terms of a medical diagnosis.

The difficulty here is getting this point across without saying that these people are merely shying away from everyday challenges that they "should" be tackling and mastering. They are not 'victims' of medicalisation. Getting the diagnosis marked a status passage, not

just for those diagnosed with it, but for their parents. The parents of children with ADHD experience as a group that this is the explanation for what has been happening; that this is reality, and now in a position to identify with the diagnosis it becomes the framework and basic perspective, for mastering the everyday which is seriously challenging because the central characteristics of ADHD put them at odds with many of the central requirements of modern function-oriented society.

The expert knowledge-producing systems, and the professionals whose work is connected to ADHD (from neurological research to special education), are all called upon and invoked to factualise, legitimate and create public space for understanding people with ADHD as a worthy people, and their group as good. Medicine lends its prestige to the diagnosis, protecting against hints and allegations about non-biological causes for misbehaviour. Special education is argued to be an entitlement to those who desire it: the language of rights is used, and interviewees were able to casually refer to specific legal paragraphs that were relevant to their case. However, the range of choices that they can demand is very limited. Parents knew their child had the right to an ILP (Individual Learning Plan), but ILPs identify the child as the source of deficiencies, not the school environment.

Minority illness?

Before medicalisation, people with ADHD were not a group and were not united by anything, except a shared stigma of being incorrigibly bad. They have become a group that is growing in strength as the diagnosis becomes more popular. But is ADHD a disability, and can ADHD-groups be considered minority groups? Homosexuals are born into heterosexual families. Similarly, parents of deaf children have sometimes been asked to consider that their children belong to another group – one they are not or cannot be part of (Solvang 2006). Ethnic-minority children, on the other hand, are born into ethnic-minority families. ADHD is somewhere between: it runs in the family, and people identify instances of possible antecedents who 'must have had it'. As a child is assessed, other family members also get drawn into the assessment, and this co-diagnosis is presented in an expression of solidarity from parents with their children. On the other hand, not everybody in the family has it, and even among those who do, it is not always visible or a problem.

How do minority groups illuminate inequalities? How do they approach equality? In this case, it is partly through pragmatism. The quotes from the interviews and articles in Stå På show that ADHD is understood as both as an a priori genetic condition and as a contingent modern illness. This is consistent with expert discourses on the causes of psychological and

psychiatric problems, where the expert scientific consensus is that a genetic predisposition together with environmental factors, leads to the problem. This was not present in all of the interviews, but those where it was not present also did not contradict this. (Nina, for example, did not want her son to go to a special school, because this was seen by her as a dead end for his education. Another interviewee, Anita, told about her father, a sailor, whose stamina and bravery made him more successful than the others.) Their pragmatic interpretation of ADHD is that its contingent status does not make it any less real.

These mothers did not primarily see themselves as victimised. Rather, they had to make a noise so someone would pay attention, and not simply explain-away their child's difference as being within the span of "normal". The parents had to argue against normalising messages, and this was the most explicit "medicalising" action they took: they resisted messages of normality, and insisted on difference. The exceptions to this were with the parents who presented themselves as not needing to take a stand, but rather neutrally accepting a diagnosis that was handed to them without them having any prior knowledge about it.

The mothers insisted that the diagnosis was not easy to get. That said, they accepted that it has to be that way. This was in strong contrast to mass media stories about the easiness of getting an ADHD diagnosis, and the academic criticisms of the diffuse diagnostic criteria. Nina, for example, told me in how strict the ICD-10 diagnostic criteria are compared to the DSM-IV criteria used in the USA. But in fact a de facto way, Norwegian practitioners do also follow the DSM (Zeiner and Arnesen 2004). The point here is that Nina was making a distinction that distanced her son's diagnosis from the immoralities associated with 'easy solutions' from the USA.

Having established the difficulty of getting the diagnosis, and their perspective that it is unfortunate but it should be that way for obvious reasons (concerns about over-diagnosis); they shifted focus to what comes *after* the diagnosis. This is now their main concern.

Norway has high participation of women in the paid workforce. Some interviewees with ADHD who told me that mothers with ADHD children tended to be at home. Family demands exceeded what they could cope with: because of the extra demands of having children with ADHD; and because of the extra load they carried as mothers with ADHD themselves. The 'extra work' of ADHD is a non-medical, lifeworld understanding used to justify their access to the sick role; as work outside the home is increasingly expected (Wærness 1998).

Is it welfare entitlements that change how Norwegian parents (mothers especially) feel, and cause the absence of 'mother-myths' that gave the mothers in research by Malacrida and Singh's guilty feelings? While there is a discrepancy between welfare state ideals and actuality ("*There is still a long way to go!*"), it seems that the ideals could be what count when it comes to culturally given feelings of guilt. They feel entitled to claim assistance, even when exactly what that claim should entail has not been fully defined.

Heritability is social

From the interviews and Stå På, there is both resistance to and use of catastrophising about future: a difficult balance. Interviewees took differing stances on how to interpret abnormal psychological research.

What happens when the biological image of humanity is transferred to the educational context? The biological view of humanity is a construction through which we interpret reality. The acquired aspects of our biology are social, when proper consideration is given to the social determinants of health and illness, and this is trenchantly argued by a number of authors. But heritability is also a social phenomenon. Witchery, the taint or prestige of social caste and class, and social phenomena such as choice of work are inherited. We 'inherit' more than just genes from our parents, and while this is clearly social in nature to social scientists, it is not interpreted in social terms among the interviewees. The social appears to be so strongly determinative, that it becomes 'inevitable'. Social fate is strongly tied to families, although not exclusively determinative in nature, just as genetic disposition is strongly influenced by family. These two are conflated and interchanged when people talk about their experiences with ADHD: *both the social and the biological are framed in bio-genetic terms*.

ADHD'ers want the successful people to come forward – they reject the notion that ADHD is a diagnosis of social deviance. Rather, the certain forms of restlessness, angst, passion, and seeking; the unstoppable drive and feeling of not fitting in around calm and tidy, organized people is what they want ADHD to be associated with.

In the final analysis, this is ultimately a collection of stories framed as interpretations of genetic inheritance. In so far as ADHD is insisted to be biological, and this understanding is premised on scientific knowledge (that understanding ADHD and knowing what it is depends on knowledge of and belief in a particular set of scientific interpretations), the expectation is that as people gain more knowledge about ADHD they will be wiser and accept it. This reflects the grand narrative of scientific progress.

Insisting that the biologically-determined behaviour has a large role to play and is fundamentally unavoidable in social settings is indicative of the *utility* of scientific biological discourses for those occasions where other understandings of behaviour weaken one's project. Biological discourses are anchored in ideas of nature and the natural. So taking a stance opposed to the diagnosis of ADHD based on the position that it reflects people's 'natural' diversity and variation is harder than taking a position that refuses to accept that people have any biologically-given personality or behavioural tendencies. Thus, the discussion can become polarised into an un-nuanced nature/nurture argument. Biological definition/against interaction and communication.

Finally, this research has illuminated an irony with the ADHD diagnosis. Parents are active in getting the diagnosis and medicalising understandings of their children's behaviour. In doing so, they buy-in to a set of beliefs of about ADHD: that the best way to 'fight' the risks of ADHD is through use of medication. But ADHD medications are provided on the ground of the risk of future problems: by seeking and accepting a diagnosis, the individual has taken on a way of thinking about themselves and they can get "back on track" with the diagnosis and therapy – this Ritalin track assumes future problems, so, with that assumption, how can they ever really distance themselves from negative images and the shadow of fate?

Conclusion

This work shows that although the Norwegian parents interviewed had to negotiate stigma on behalf of their child and their whole family, they were not vulnerable to "mother-blame" in the same way that mothers researched in some liberal English-speaking countries have been found to be (Malacrida 2003, Singh 2005). They agreed with professionals that "investigation" of the family is a vital part of rigorous assessment for ADHD. But in that process where the families of children getting diagnosed also have the professional gaze directed at them, it seems reasonable to modestly suggest that either they did not have the same burden of proof, or else it was not a blaming gaze. Those who had felt they were blamed at some point found that getting a diagnosis had changed that; as individuals and as a group, they brushed off mother-blame with confidence. By contrast, in England and Canada, mother-blame was persistent even after a diagnosis was given.

Some informants said they knew "someone" who had been blamed and whose living arrangements had come under close scrutiny – but it had not happened to them. It cannot be entirely ruled out that it is an *untellable* topic. One of the informants felt she had been directly blamed; but even she explained how this changed after she got her own ADHD diagnosis and stopped the self-medication that may also have drawn attention to her.

While not feeling blamed by others or blaming themselves, the Norwegians interviewed for this research felt stigma and grief connected to their 'genetic fate'. The medicalised stigma concerned behavioural and learning challenges connected to school and social interaction; stigma was also connected to the risk of future problems such as employability, being able to manage without social services, drug taking and other criminal behaviour, and psychosis. These are seen as inevitable without the therapeutic intervention of the "Ritalin track". A grandfather was worried his son's ADHD might have been inherited by his son, and was relieved to see signs that he was not burdened with it.

Modernity has created the disability of ADHD, as the traits that lead to diagnosis run counter to modern technical requirements. *ADHD-Norge* as a social movement is pushing for more acceptance and help. Their problems have been identified as 1. stigma concerning the diagnosis and 2. insufficient knowledge about what defines good facilitation and adaptations. The first is a problem that concerns social diversity/normality and that people with ADHD cannot conform to all school expectations and often lack friends. If inattention and hyperactivity were acceptable, there would be no problem and no diagnosis. The "impairment" is only relative and the disability is socially created. The second problem is in

developing their weapon against this: knowledge and assistance. They have "a long way to go", but one hindrance they will not expect to encounter to the same extent as parents (especially mothers) in the aforementioned "English-speaking countries" (for all the weaknesses of that generalisation) and liberal welfare states. Their demands for assistance are a culturally-given entitlement and right to help, and were *not* characterised by unwanted attention from professionals of a moral or psychoanalytic nature: the diagnosis did not make the mother into the deviant. (It is prudent to note there may be methodological bias here: informants were all already members of the ADHD Association which indicates reasonable confidence about the diagnosis; and feeling good about themselves as parents could have influenced their decision to agree to be interviewed). However, there was a tendency for mothers to also get diagnosed themselves when their children were under assessment. The informants utilised their own diagnoses in ways that were presented as supporting their children; and took their own diagnosis as confirming the hereditariness of ADHD's aetiology. This could be stigmatising to the family, but it was not all lumped on the mothers' morality. In Stå På it is insisted that mothers, not just fathers, can be the genetic ADHD link. Doing this gives more legitimacy to the elaboration of the diagnosis to include the 'quiet', 'inner' undiagnosed form (where one seems to manage to conform, but suffer badly). Mothers with diagnosed children (in Stå På and the interviews) feel lucky that they can put a name on their problems, and get the support provided through membership in the Association.

Stigma towards the behaviour itself (as opposed to the idea of the diagnosis) is a product of modernisation. Alternative education arrangements were found Hilde's father at a time when education was not a necessity as today. Anita's father was able to provide well for his family, and build their social standing, at a time when fishing was more in demand. Hilde and Anita's fathers did not have to meet demands of modern culture such as taking extended education.

Recapturing the "good ADHD stories" from the family archive is a challenge to ADHD-sceptical discourses. They explain how changed conditions create the "impairment", and that the diagnosis is a tool for getting help. This pragmatism is seen as the route to acceptance of difference and positive self-image. It has been suggested that there are trends towards increasing acceptance of difference (Eriksen and Breivik 2006); but psychosis and criminality remain socially unacceptable. These are associated with "severe" ADHD in professional literature, and parents handle that association in various ways: some reject it, others explain that the treatment therapies change it. In this way, the parents support professional power and are dependent on therapies. The ADHD group rely on expert

knowledge to make their impairment visible. At the same time, people identify with the diagnosis, and recognise themselves in other people's narratives. Because of this, a positive, de-stigmatised image for ADHD is important for self-image. The ADHD group want to promote understanding that the disability is circumstantial and contingent, because many people with ADHD do have wonderful abilities, energy and stamina. Parents of ADHD children believe their children can shine under the right circumstances.

The informants think that the ADHD cause "*still has a long way to go*". This is heroic: in addition to helping children with learning problems and problems making friends, burn out, frustration, dependence on pharmaceutical therapy, and various risks, they also face stigma and fate.

Informants think the diagnosis "*would be a lot better if it wasn't so stigmatised*". Parents of children with ADHD want dignified work opportunities, therapeutic intervention, and reasonable independence from social services.

Is ADHD "real"? Yes, in the sense that we are all in a situation characterised by contingencies and acting on impulses. ADHD is the medical labelling of a situation; one contingent on the interplay of a biological condition, individual psychology, cultural conditions and social action and communication. This 'social psychological' view of ADHD does not reduce the diagnosis to medical fact, nor reduce it to an instance of social control. Parents of children with ADHD knew their children were unable to meet certain expectations: they want difference to be acknowledged so their children's behaviour is not seen as wilful, and they can get assistance for school, work and living arrangements. At the same time, informants reject the label in some contexts. Diagnosis is seen as being the only practical solution, but they use it "at a price".

Does the therapy create dependence? It seems so, but it is also liberating: this research indicates that after receiving a diagnosis, the women interviewed did not accept 'mother-blame'. In the modern setting, numerous forms of deviance are regulated by health experts. Medical authority also has a dark, disciplining side; but it is medical experts who give access to the liberating aspects of the sick role. The medical authority girdering the diagnosis and the sick role is difficult for laypeople to question. Since disease is legitimated by medical authority, patients conform to medical interventions. But the understandings of what the disease mean in practice do not only come from medicine; rather, new meanings are created with the help of the Association out the parents' own cupboard of family stories and ideas about themselves.

Risk discourse is dominant in the assessment paradigm that identifies ADHD. It displaces the subject with risk factors. Risk has largely replaced dangerousness as creating a basis for expert intervention. Parents of children with ADHD want expert medical intervention for the liberating aspects of the sick role it gives access to. They want expert pedagogical assistance, and practical assistance from the welfare apparatus to enable independence for adults with ADHD. Parents see this as something they ought to have a legitimate claim to based on their contribution to society, and this is in keeping with the typical characteristics of Nordic welfare state cultures. They want people to understand that their children reaching legal age of independence does not necessarily bring with it an ability to cope with adult responsibilities. While expert intervention is a critical part of the status passage into being an ADHD'er, the diagnostic paradigm tends to make the person invisible behind 'risk factors' and labels connected to risk factors. The Association tries to counter this by saying that all people with ADHD are unique.

This work has shown how treatment and strategies, from differing biomedical and psychosocial traditions respectively, go hand in hand in practice and even necessitate each other. We have also seen how taking an 'ambivalence perspective' on medicalisation enables a more nuanced and complicated picture to emerge. Parents of children with ADHD negotiate in what they believe are their children's best interests and do their utmost to help them. The parents' self-interest in looking good and having a governable child were considered; but finally it was argued that to focus on this would be to miss the point. The parents' primary consideration was to get help for their children.

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Kristen Fjellestad, "*Gode sjåførar med AD/HD? [Good drivers with AD/HD?]*" pp.7-10

Audun Traagstad, "*Ikke fått diagnosen AD/HD – men kjenner meg dels igjen! [Haven't got the diagnosis AD/HD – but partly recognise myself in it!]*" pp. 28-29.

Kikki, "*Voksen kvinne med diagnose AD/HD. [Adult women with diagnosis AD/HD]*" pp. 30-32.

Fra Fylkes- og lokallagene: Finnmark, "*Seminar om AD/HD, TS og OCD.*" Pp. 35-36.

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Beate Heide, "*Makk i ræva [Have you got worms?]*". Pp.20-21.

Per Jarl Elle, "*Myter om barn med AD/HD [Myths about children with AD/HD]*". p.22

R.W., "*Altfor synlig, men usynlig [All too visible, yet invisible]*". Pp.31-32.

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Tor Eikeland, "*Generalsekretærens spissformulerte: Det står skrevet… [The General Secretary's criticism: It has been written…]*" p. 5.

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Marit O. Bromark, "*Sjenert. Hyper. [Shy. Hyper.]*" Pp.19-22

Liv Sook Teigen, "*Når barnet møter ADHD-debatten. [When the child meets the AD/HD debate]*." pp. 27-30.

Book review by Bothild Bendiksen, " *Hyper: Pernille Dysthe*." p.35

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'Rita Linn', "*En mors dilemma: Noen rode, noen blå? Noen små med sukker på? Eller holder det med en skje tran? [A mother's dilemma: A few red, a few blue? A few little ones with sugar on top? Or will a tea-spoon of codliver oil do?]*" pp.12-15.

'Rita Linn', "*Det kommer fra faren… [It's from the father…]* " pp.23-27.

Book review by Gunnar Gjengset, "*Aldri for sent å skaffe seg en lykkelig barndom. [Never too late for a happy childhood]*" Pp.35-47

Kåre Bendiksen, "*Om kriminalitet og ADHD [On criminality and AD/HD]*". Pp.38-40

Appendices

Appendix 1: Presentation of research to potential interviewees

I read this out at an ADHD meeting where I hoped to meet interviewees.

> *"Til tross for at ADHD har blitt akseptert som en medisinsk tilstand i mye av den engelskspråkelige verden, har ikke denne medikaliseringsprosessen gjenspeilet aksept av diagnosen, eller blitt en løsning til alle problemer.*
> *De tilgjengelige behandlingen for ADHD er i hovedsak medikamenter. I noen tilfeller forandrer medisinsk behandling aksept av problematisk atferd, eller fører til nedsatt tilbud om andre former for hjelp og støtte: dette har vært tilfelle i deler av USA hvor enkelte barn får betinget skoleadgang (de må ta medikamenter eller får de ikke går på skole). På den andre siden, fins der foreldre i deler av England og Canada som er desperat å få en utredning og behandling for barnene sine, men den veien er stengt enten på grunn av faglig skepsis* mot sykdommen selv, eller større tro på sosial og psykologisk behandling av familien og barnet.*
> *Jeg ser dette som en slags kamparena over hvem som skal få siste ordet, og hvem som har største autoritet over barnets atferdsproblemer og sykdom: legen, foreldre, lærer, PPT, og så videre.*
> *Der fins også de som mener at ADHD er på det beste overdiagnostiserte, og på det verste helt uten vitenskapelig eller organisk basis. Disse skeptiske stemmer har sikkert blitt hørt av noen av de foreldre som både mener at barnet både har ADHD og har behov for medikamenter, eller som mener at medikamenter er det eneste reelle valg de har.*
> *Jeg skriver masteroppgaven min i lys av dette, og håper at noen av dere har lyst å bli intervjuet."*

Some were provoked by this comment, and somebody cried out, "Fordømmer! Det er fagfolk som dømmer! Andre viser aksept." ("*Prejudice! It's the specialists who judge! Others are accepting.*")

Appendix 2: *Email request for an interview*

Subject: ADHD forskning fra UiB - epost fra Justine Parer

Hei –
Vi traff på ADHD møtet i november hvor jeg presenterte min masteroppgave. Jeg lurte på om det er mulig å få et intervju med deg i løpet av de neste ukene?
Jeg vil minne deg om at det vil være full anonymitet. Det vil si at du skal siteres anonymt, og din identitet skal elles være skjult. Dette forsknings prosjekt har vært godkjent av NSB (Norsk samfunnsvitenskapelig datatjeneste, http://www.nsd.uib.no/index.html).

Med vennlig hilsen,
Justine
Masterstudent i sosiologi, UiB

Follow-up email (example)

Hei –

Jeg var i kontakt med deg før den hektiske juleperioden angående intervju til masteroppgave. Er det mulig å treffes for et intervju neste uke? Vi kan treffes enten på (x), (y), eller kanskje hjemme hos deg hvis det er enklere.
Jeg vil minne deg om at det vil være full anonymitet. Det vil si at du skal siteres anonymt, og din identitet skal elles være skjult. Dette forsknings prosjekt har vært godkjent av NSB (Norsk samfunnsvitenskapelig datatjeneste, http://www.nsd.uib.no/index.html).

Med vennlig hilsen,
Justine Parer
(Kontakt detaljer).

Appendix 3: Interview Guide

Takk for at du funnet tid til meg i dag. For det først vil jeg minner deg at dette prosjektet har blitt godkjent av NSD og at du og de du nevner i intervjuet skal være godt anonymiserte. Du kan trekke deg når som helst, enten med å ta kontakt med meg, eller veilederen min eller Sosiologisk instituttet ved UiB. Er det greit med deg om jeg tar opp intervjuet på bånd?

When did you discover your child had ADHD? When did you first learn about ADHD? (Were you ever sceptical about it, and if so, when did you change your mind?)

GUILT AND SUFFERING

Do you feel blamed? Directly or rather more indirectly – for instance are you made to feel your efforts have been inadequate? It can be anguishing to see somebody you love suffer. Do you feel that, and does it make you feel you should do more, or is it just exhausting?

Has getting this diagnosis changed any of that? Provided some relief?

Have you curtailed extra-familial activities in order to look after the child with ADHD? Should you have to?

Do you feel you should have acted earlier, or have you done your best under the circumstances?

What do you think about the suggestion that ADHD is genetic? Do you suspect you have it? Are you worried about other family members? Do you wish there was a conclusive test?

BUREAUCRACY

Have you had confrontations with authority figures (doctors, teachers, special educators, bureaucrats)? If so, how did you act – were you cowed into silence, or did you assert yourself as equally expert/your own authority?

Do you go to meetings with teachers or doctors alone, or do you take somebody (aside from the child, such as another family member, a friend, or perhaps someone from *ADHD-Norge*) with you for moral support?

Have you had to fill out a lot of forms? Do you feel you have been fobbed-off or intimidated by bureaucrats?

SCHOOL

Has the school helped? In what ways (eg. accepting the diagnosis, getting support, enrolling the PPT, carrying out the ILP, making you feel different about the child's school performance)?

Were you pressured to medicate the child? Has the school been helpful in administering doses?

What's your impression of PPT? (Are they well-meaning? Do they care? Are they skilled enough? Do they have the resources they need?)

Do you have a role in your child's ILP? Do they use "team" rhetoric? Do they want your input?

What do you make of the Norwegian school system overall? (Open classes, notions of equality among students/not streamed, teaching standards, resources, length of schooling)

How do parents see the child's reflexivity? Will it ever develop?

MEDICAL CONTACT

How would you describe your relationship with your doctor? Were you happy with the diagnosis process – do you feel they whipped out the prescription pad too early without even looking at the kid; or was it the opposite, that they didn't take the medical issue seriously and made you feel incompetent or stupid?

Was there a placebo trial?

We know medicine is rarely a panacea for ADHD. What kind of problems remain with you since the diagnosis, and can you think of any new problems that have resulted from it? Have new problems accompanied the medicating itself, the doctoring, and labelling of your child?

SUCCESS

What do you envisage as a successful life? How much of this problem is behaviour and performance? What do you think of adults with ADHD?

METAPHORS

Can you describe something you think ADHD is similar to? Is it like another experience you've had before? Is it like another illness? Is it separate from your child? If ADHD was a "thing" in your child, what would it be?

Appendix 4: ICD-10, chapter 4, Mental and behavioural disorders

Behavioural and emotional disorders with onset usually occurring in childhood and adolescence (http://apps.who.int/classifications/apps/icd/icd10online/?gf90.htm)

F90 **Hyperkinetic disorders**

A group of disorders characterized by an early onset (usually in the first five years of life), lack of persistence in activities that require cognitive involvement, and a tendency to move from one activity to another without completing any one, together with disorganized, ill-regulated, and excessive activity. Several other abnormalities may be associated. Hyperkinetic children are often reckless and impulsive, prone to accidents, and find themselves in disciplinary trouble because of unthinking breaches of rules rather than deliberate defiance. Their relationships with adults are often socially disinhibited, with a lack of normal caution and reserve. They are unpopular with other children and may become isolated. Impairment of cognitive functions is common, and specific delays in motor and language development are disproportionately frequent. Secondary complications include dissocial behaviour and low self-esteem.

Excludes: anxiety disorders
mood [affective] disorders
pervasive developmental disorders
schizophrenia

F90.0 **Disturbance of activity and attention**

Attention deficit:
· disorder with hyperactivity
· hyperactivity disorder
· syndrome with hyperactivity

Excludes: hyperkinetic disorder associated with conduct disorder

F90.1 **Hyperkinetic conduct disorder**

Hyperkinetic disorder associated with conduct disorder

F90.8 **Other hyperkinetic disorders**

F90.9 **Hyperkinetic disorder, unspecified**

Hyperkinetic reaction of childhood or adolescence NOS
Hyperkinetic syndrome NOS

F98 **Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence**

A heterogeneous group of disorders that share the characteristic of an onset in childhood but otherwise differ in many respects. Some of the conditions represent well-defined syndromes but others are no more than symptom complexes that need inclusion because of their frequency and association with psychosocial problems, and because they cannot be incorporated into other syndromes.

F98.8 Other specified behavioural and emotional disorders with onset usually occurring in childhood and adolescence

Attention deficit disorder without hyperactivity, Excessive masturbation, Nail-biting, Nose-picking, Thumb-sucking.

Appendix 5: DSM-IV Criteria for ADHD

I. Either A or B

A. Six or more of the following symptoms of inattention have been present for at least 6 months to a point that is disruptive and inappropriate for developmental level.

Inattention

- Often does not give close attention to details or makes careless mistakes in schoolwork, work, or other activities.
- Often has trouble keeping attention on tasks or play activities.
- Often does not seem to listen when spoken to directly.
- Often does not follow instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions).
- Often has trouble organizing activities.
- Often avoids, dislikes, or doesn't want to do things that take a lot of mental effort for a long period of time (such as schoolwork or homework).
- Often loses things needed for tasks and activities (e.g. toys, school assignments, pencils, books, or tools).
- Is often easily distracted.
- Is often forgetful in daily activities.

B. Six or more of the following symptoms of hyperactivity-impulsivity have been present for at least 6 months to an extent that is disruptive and inappropriate for developmental level.

Hyperactivity

- Often fidgets with hands or feet or squirms in seat.
- Often gets up from seat when remaining in seat is expected.
- Often runs about or climbs when and where it is not appropriate (adolescents or adults may feel very restless).
- Often has trouble playing or enjoying leisure activities quietly.
- Is often "on the go" or often acts as if "driven by a motor."
- Often talks excessively.

Impulsivity

- Often blurts out answers before questions have been finished.
- Often has trouble waiting one's turn.
- Often interrupts or intrudes on others (e.g., butts into conversations or games).

II. Some symptoms that cause impairment were present before age 7 years.

III. Some impairment from the symptoms is present in two or more settings (e.g. at school/work and at home).

IV. There must be clear evidence of significant impairment in social, school, or work functioning.

V. The symptoms do not happen only during the course of a pervasive developmental disorder, schizophrenia, or other psychotic disorder. The symptoms are not better accounted for by another mental disorder (e.g. mood disorder, anxiety disorder, dissociative disorder, or a personality disorder).

Based on these criteria, three types of ADHD are identified:

1. *ADHD, Combined Type*: if both criteria 1A and 1B are met for the past 6 months
2. *ADHD, Predominantly Inattentive Type*: if criterion 1A is met but criterion 1B is not met for the past six months
3. *ADHD, Predominantly Hyperactive-Impulsive Type*: if Criterion 1B is met but Criterion 1A is not met for the past six months.

(From DSM-IV, APA 2000)

Appendix 6: ”Ritalin misbruk blant unge”

NORGE I DAG

23rd September, 2008 – NRK Rogaland. Reporter Gunnar Morsund.

Vertinne: *Først i Norge i Dag, om vanedannande ADHD medisin som er på avvegar i Rogaland. Ungdommar fortel at Ritalin bli seld i Eigersund og brukt samen med alkohol. Alarmen har gått til foreldre og Ungdomskontakt.*

Reporter: *Dette er medisin Ritalin som hjelper personar med ADHD, men nå fortel ungdommar i Eigersund at slike tablettar blir omsett som rusmiddel. Tablettane blir blanda i lag med alkohol for å få ein ekstra rus.*

Ungdom: *Eg ser ofte at dei blir seld på byen og sånn, at nokon brukar det til å dope seg og sånn.* **Reporter:** *Kva synes du om det?* **Ungdom:** *Nei det er ikkje bra. Må få ein slutt på det.*

Reporter: *Ungdomskontakten i Eigersund trur ikkje at ADHD medisin har ein stor utbreiing. Likevel har alarmklokkene gått og foreldra og ungdomsskulen er varsla.*

1. Kvinne: *Dei fortel jo at dette kan vere ein grei måte å få rus på, sånn at mor og far slepp å oppdage det, ikkje sant. Dei slepp å drikke fult så mykje som dei gjerne må for å få same rusen med alkohol. Og då kan dette vere greitt pluss at dette med ADHD tablettar er veldig billig.*

Reporter*: Du synes det er bra at undomskontakten tek tak i dette?* **Ungdom:** *Ja det er jo veldig bra, for det er jo dumt at folk skal dope seg på det, då får jo ikkje folk tatt medisinen sin når dei selga den.*

Reporter: *Misbruk av ADHD medisin er nok ikkje einestående for Eigersund. Rogaland Psykiatriske Sjukehus er i jamn mellomrom i kontakt med politiet for dei er bekymra for at Ritalin tablettar er på avvegar. For større dosar <u>vil</u> føre til avhengigheit.*

2. Kvinne: *Og her er jo disse medikamenta, kopla jo inn saman med de andre, kan medføre, vi vet jo at det kan føre til store overopphopingar av psykosar som er alvorlige sinnslidingar blant ungdommar som ruser seg. Ja dette er veldig farleg, skadeleg ting.*

1. Kvinne: *Me vaksne må ta inn over oss at me gjerne fort seier at ”*Gjerne tar eg ein tablett for det og så føler eg meg mye betre*”. Det er klart at me sender noen signaler til ungdomsgenerasjonen at ”*Her med berre ein tablett, so kan den løyser so mangt*”. Og der må me nok innrømme at me er rollemodellar, og det er på godt og på vondt.*